DEFINING A GOOD DEATH FOR RESIDENTS IN LONG-TERM CARE

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ABSTRACT

JEAN MUNN: Defining a Good Death for Residents in Long-term Care
(Under the direction of Sheryl Zimmerman)

Each day 1000 older adults die in nursing homes and another 500 in residential care/assisted living facilities. In addition, 30% of Medicare deaths in hospitals are recent transfers from long-term care, indicating that long-term care facilities are a major provider of end-of-life care for older adults. Yet, end of life care in these settings is largely unexamined. One reason for this omission is the challenging nature of the work as described in the introduction to this dissertation. However, the dissertation addresses those challenges and gives voice to the needs of residents who die in these settings through three papers based on the input of residents, bereaved family members, and staff caregivers. The first paper, Dying in Long-Term Care: Insights from Residents, Family Members and Staff, is based on ten focus groups in which participants were asked to describe a good death. They The second paper, Defining a Good Death: Family Members Speak, describes family responses to two open-ended questions regarding what was best and what could have been done better in the last month of the resident’s life. The third paper, Measuring the Quality of Dying in Long-Term Care, introduces a new measure, of the Quality of Dying in Long-term Care (QOD-LTC), to be used for future research in these settings. Each paper makes a significant contribution to the literature, both by describing what is done well and where improvements can be made.
DEDICATION

This dissertation is lovingly dedicated to my mother, Angell Warren Correll, who taught me about life and death by her example, and who inspired my research career by her courage in the face of Alzheimer’s disease. It is also dedicated to my husband, John Walden Munn, who tirelessly supported me during the completion of this work.
ACKNOWLEDGEMENTS

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CHAPTER 1
INTRODUCTION

This dissertation examines death and dying of residents in long-term care by listening to the voices of residents, family caregivers, licensed nursing staff, and paraprofessional care providers who have been directly involved in the end-of-life experience in nursing homes and residential care/assisted living facilities. This is not an easy task as there are multiple methodological and conceptual challenges associated with end-of-life research in general and long-term care research in particular.

However, the need for such research is great. There is nation-wide concern over care of the dying (Grady, 2005) and a need for setting-specific research (Ramsey, 1999; Kayser-Jones, 2002; Sulmasy, 2002) based on input from dying individuals or their families (Clark, 2003; Singer & Wolfson, 2003). Further, the rapid growth of the segment of the population described as older adults (65 years of age or older), makes this stratum an important focus for those who seek to improve end-of-life care through research (Grady, 2005).

As the number of older adults has increased, so has the number living in long-term care. Between 1977 and 1999, the nursing home population increased 27% (i.e. from 1.28 million to 1.63 million, of whom 1.5 million are over the age of 65) (Decker, 2005; US Department of Health and Human Services, 2003). Annual mortality rates for this population are as high as 34% during the first year of residence and 24% thereafter (Kiely & Flacker, 2003).
Another rapidly growing site of death gaining recognition are residential care/assisted living facilities. This supportive environment houses approximately one million older adults who evidence mortality rates of 14-22% annually (Golant, 2004; Zimmerman, Sloane, Eckert, et al., 2005), with approximately 28-33% of residential care/assisted living residents remaining in the facility until death (Mezey, Dubler, Mitty & Brody, 2002).

Therefore, although only a small percentage (approximately 6%) of older adults in the United States live in long-term care (Pynoos & Golant, 1996; Jones, 2002; Hetzel & Smith, 2001), a much greater proportion of deaths of older adults (23%) occur there (Facts on Dying, 2004). Taken together, these demographic trends guarantee that nursing homes (and indeed all long-term care settings) “are now and will continue to be, the major provider of care for the dying” (Teno, 2002, p.2).

The dissertation introduction will summarize the methodological and conceptual challenges associated with examining the dying experience in long-term care such as choosing appropriate methodologies, using of surrogate respondents, and establishing the timing of research studies. Then, the introduction will describe available resources to overcome these challenges which will promote meaningful research into this timely issue. Some resources include existing theory, a conceptual framework, and existing research conducted in other settings. The three papers that comprise the dissertation will be integrated into these discussions throughout. Finally, there is a description of the dissertation contribution to research and the doctoral candidate’s research agenda.

Methodological Challenges

There are multiple methodological challenges associated with end-of-life research in all settings. One essential problem is determining who is appropriate for inclusion in such
studies. This problem stems from the challenging issues of determining who is dying (Teno & Coppola, 1999; Patrick, Engelberg & Curtis, 2001; Hickman, Tilden, & Tolle, 2001; Fowler, Coppola & Teno, 1999) and at what point residents cease to be seriously ill and begin to die (George, 2002; Finucane, 1999; Grady, 2005). Further, end-of-life research is challenging as residents may be unable or unwilling to participate in prospective research studies (SUPPORT Principal Investigators, 1995; Hickman, Tilden & Tolle, 2001). In fact, earlier studies found that one in three patients could not be interviewed while actively dying or during the last week of life (Patrick, Engelberg & Curtis, 2001; Hickman, Tilden, & Tolle, 2001). These difficulties have led to a disproportionate number of end-of-life studies related to cancer deaths, a disease with the most predictable trajectory (Morris, Mor, Goldbery, Sherwood, Greer, & Hiris, 1986; Kayser-Jones, 2002; O’Boyle & Waldron, 1997).

Retrospective end-of-life studies represent one method of mitigating these problems by allowing researchers to specify study samples more accurately, reduce missing data and respondent burden, and obtain data about a larger number of subjects (Teno, 2005; Fowler, Coppola & Teno, 1999). Indeed, Fowler and colleagues (p. 115) state: “If the goal is to examine the quality of care in the last month of life, the sure way to do that is to identify patients after they have died.” In the long-term care setting, these problems are exacerbated by long periods of chronic illness with multiple morbidities (Harrington, Carillo, & Wellington, 2001; Jones, 2002) further reducing prognostic accuracy. In one recent study of death in nursing homes and residential care/assisted living facilities, approximately 60% of deaths were expected by staff and slightly more than half were expected by family members (Hanson, unpublished draft). These findings suggest that retrospective studies are essential for adequate representation of older adults who die in these settings.
However, post-death data collection requires the use of surrogate respondents, a practice widely debated as reducing validity in healthcare research (Higginson, Priest, & McCarthy, 1994; McPherson & Addington-Hall, 2003; Hinton, 1999). Results from studies attempting to determine the validity of surrogate responses are contradictory (Neumann, Araki & Gutterman, 2000) and report confounds such as bereavement, age of surrogates, gender of surrogates, and the nature of the relationships between surrogates and patients as affecting validity based on congruence with patient reports (McPherson & Addington-Hall, 2003; Miaskowski, Zimmer, Barrett, Dibble & Wallhagen, 1997; Clipp & George, 1992; Teno & Coppola, 1999).

In long-term care, high rates of cognitive impairment (ranging from 25% to 95% in nursing homes [Magaziner, et al., 2000; Hall, Schroder, & Weaver, 2002] and 18% to 67% in residential care/assisted living facilities [Phillips, Holan, Sherman, Spector, & Hawes, 2005; Burdick, et al., 2005]) render approximately one-half of residents unable to make decisions independently or provide valid evaluations of care. Therefore, family members often actively participate in healthcare decisions, monitor care provision (Corder, Woodbury & Manton, 1998), and can provide data not available from residents.

Indeed, eliminating surrogate respondents from research conducted in long-term care settings is not an option. Not only would there be untenable reductions in sample size, samples would be biased, excluding the most vulnerable portion of the population, those who are unable to communicate their needs (Fowler, Coppola, Teno, 1999; Higginson, Priest & McCarthy, 1994; McPherson and Addington-Hall, 2003; Desbiens, et al., 1996). As some residents have no available family, the use of staff surrogate respondents is also appropriate. Further, utilizing both family and staff respondents allows for triangulation of data sources,
comparisons within and among groups, and documentation of patterns of congruence and
difference, a method supported by experts (Steinhauser, 2005).

Conceptual Challenges

It is also challenging to determine which aspect of quality is the research focus. There
are three related constructs: quality of care, quality of life, and quality of death associated
with end-of-life research (Steinhauser, Clipp & Tulsky, 2002) which are related but not
indistinguishable. Each has unique as well as common components. They are established
constructs for examining healthcare quality and provide a rubric for understanding what is
important at the end of life.

Quality of care, especially palliative care, is a multi-dimensional construct including
physical, emotional and spiritual care components (WHO, 2004; American Geriatrics
Society; Sulmasy, 2002; Engel, 1977; White, Williams, & Greenburg, 1996). One
characterization of care is that it is administered to care recipients by the care providers
regardless of the recipients’ participation. Therefore, quality of care can be assessed by care
giving staff (Higginson & Romer, 2000), although, currently, experts also espouse consumer
satisfaction as an additional outcome measure of care quality (Teno, 1999; Teno, 2005)

Logically, quality of life is, in part, an outcome of quality of care. It is hard to
imagine excellent quality of life without adequate pain management and personal hygiene
(Koenig, 2002; Kaasa, 2000). However, quality of life consists of additional components
such as personal expectations (Deiner & Suh, 1997; Higginson & Romer, 2000) and
individual characteristics such as clinical status or availability of social support (Stewart,
Teno, Patrick, & Lynn, 1999) and therefore, is more subjective than quality of care.
Quality of death is more complex. Quality of care and quality of life are components of quality of death, yet examining quality of care and quality of life does not fully explain quality of dying. There are unforeseen circumstances surrounding the dying process and the moment of death that have a significant impact on the quality of dying. Therefore, unlike quality of care and quality of life that may be measured or examined prospectively, quality of death must be examined post-death. A literature-based definition of a good death is the degree to which the dying person’s preferences are met. However, it is essential to make this determination in the context of circumstances of death that can neither be foreseen nor avoided (Patrick, Engelberg & Curtis, 2001).

For example, most older adults (65%) wish to die at home, but only 20% do so (Temkin-Greener & Mukamel, 2002). There are unforeseen circumstances (e.g., acute or chronic medical conditions, severe functional impairment) that prohibit remaining at home until the time of death (Sankar, 1993). This is particularly true for older adults who have long periods of chronic illness, dementia and related behavioral problems, and functional disabilities that require round-the-clock care provided by multiple caregivers in structured environments (i.e., nursing homes and residential care/assisted living facilities) and for whom, even the best-intentioned families are unable to care (Teno, 2002).

In this dissertation, one paper, *A Good Death for Residents in Long-Term Care: Family Members Speak*, examines the process of care from the family members’ perspective. The family members answered questions about what was done by family and/or staff during the last month of life that was particularly helpful and what could have been done better. Care provision is the focus, although family members identified dimensions of care that influence the quality of the decedents’ lives. For example, family members spoke of “being
there” with the resident. They went to the facility and visited with the resident (care provision), which influenced the resident’s quality of life (in this case, an outcome of care) during the last month of life. Notably, these data further suggest that family members also benefited from visiting the resident.

However, *Dying in Long-Term Care: Insights from Residents, Family Members and Staff* presents focus group responses to questions related to the quality of death and dying. That is, initially respondents were asked about a good death and a bad death. Not surprisingly, respondents talked about the quality of death as an outcome of quality of care (e.g., pain management resulting in a pain-free death), quality of life (e.g., residents equated a good life with a good death), and the circumstances of death (e.g., short duration, surrounded by family and friends).

This focus group study and resultant paper capture both the prospective views of residents and the retrospective insights of residents, bereaved family members, licensed staff and paraprofessional care providers. Further, the data from these focus groups illustrate the difficulty in separating structure, process and outcome. Although this model is an established manner of looking at healthcare quality (Institute on Medicine, 1997; Lynn, 1997; Stewart, Teno, Patrick, & Lynn, 1997), the allowance for open-ended discussion of multiple constructs reflects the real life confound in which the structure, process, and outcomes of care are interwoven. For example, when describing a bad death (an outcome), one resident described being “hooked up to machines” (process of care) and “hanging on and hanging on” (quality of living and quality of dying [also processes]).

The quantitative paper, *Measuring the Quality of Dying in Long-Term Care*, describes an outcome measure of the quality of dying, the Quality of Dying in Long-Term
Care (QOD-LTC), administered post-death to bereaved family members and staff care providers. The retrospective nature of the instrument allows for measuring the quality of death and dying. Items related to quality of care (e.g., cleanliness care) and quality of life (e.g., maintaining dignity) are included as these constructs contribute to the quality of dying. Further, the QOD-LTC draws in-part from an instrument (the Quality of Life at the End of Life [QUAL-E]) developed in the ambulatory care setting and prospectively measuring the quality of life (Steinhauser et al., 2002). While some were drawn directly from the QUAL-E and some were added based on earlier research, some of the QUAL-E domains were retained. For example, the domain of “relationship with the healthcare system” has been retained from the earlier measure; however, items related to care by nursing staff and physical touch have been added to reflect the long-term care healthcare system. In spite of these multiple challenges, there are resources that enable researchers to go forward.

Resources

The dissertation drew upon three resources to develop the studies and papers herein: theory; a conceptual model; and qualitative methods, specifically grounded theory and content analysis. These resources combined to guide the work while expanding the doctoral candidate’s research skills and knowledge.

Theory

While the challenges to research at the end of life are evident, there are resources that enable researchers to address this important topic. In the United States, focus on a good death emerged as an issue in medical and social sciences approximately 35 years ago. It appears to have grown out of the institutionalization of the Hospice movement that began in the United Kingdom (Patrick, Engelberg, & Curtis, 2001). Concurrently, there have been major
developments in medical care of the dying (Ersek & Wilson, 2003; Kayser-Jones, 2002; Teno, Weitzen, Welle, & Mor, 2001) and the introduction of multi-dimensional definitions of palliative care including physical, social, psychological and spiritual domains (World Health Organization, 2004; Sulmasy, 2002).

At the same time, seminal theoretical work provided new paradigms for examining the dying process. Multiple theories developed concurrently, including stage theories (Kubler-Ross, 1969; Buckman, 1993), task-based theories (Kalish, 1979; Corr, 1992); and living dying interval (Engle, Fox-Hill & Graney, 1998; Engle, 1998). Among these, the task-based theory developed by Richard Kalish (1979) and modified by Corr (1992) resonates for application in long-term care for several reasons.

These task-based theories (in contrast to stage-based theories of Kubler-Ross [1969] and Buckman [1993]) recognize the importance of human agency: dying persons participate in and make decisions about the individual dying process. In addition, Kalish (1979) recognizes the social context of dying and collaborative nature of performing the tasks associated with dying. These features of task-based theory are especially salient in long-term care as it is the nature and mission of long-term care that caregivers perform supportive tasks for physically and cognitively impaired residents.

Further, an examination of these tasks (see Table 1.1) indicates that dying is a multi-faceted process, a theme reflected in contemporary literature (Cella, 1994; Sulmasy, 2002; Steinhauser, et al., 2000, 2001; Teno, 1999). For example, dealing with loss (Task 2) deals with both physical and psychosocial loss. Likewise, arranging for care needs (Task 3) relates to both physical needs and other
priorities. Task 4 (planning the future) indicates that one, even in the terminal state, has reason to hope for a better outcome.

Table 1.1: Kalish’s Eight Tasks of the Dying Person

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<th>TASK</th>
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<tr>
<td>1. Contemplating arranging affairs</td>
<td>The dying person has knowledge of death; he/she may undertake tasks alone or with others</td>
</tr>
<tr>
<td>2. Dealing with loss</td>
<td>The dying person must deal with loss of self and loss of others; he/she must consider what his/her death will mean to those who survive him/her while dealing with the loss of his/her whole world; considered by Kalish the most difficult task confronting the dying person.</td>
</tr>
<tr>
<td>3. Arranging for future and other care needs</td>
<td>The dying person may need to consider how he/she wants to manage pain, where he/she wants to die and ultimately what are his/her priorities for end-of-life care.</td>
</tr>
<tr>
<td>4. Planning the future</td>
<td>The dying person recognizes that there is at least an immediate future. The knowledge of death changes the meaning of time and futurity for one who knows he/she is dying.</td>
</tr>
<tr>
<td>5. Anticipating pain, discomfort, and functional decline</td>
<td>The dying person anticipates pain, discomfort, and physiological and cognitive declines in functioning, ultimately resulting in loss of identity/sense of self. The planning task is confounded by uncertainty of the degree, severity and frequency of the symptoms with which one must deal.</td>
</tr>
<tr>
<td>6. Coping effectively with the death encounter</td>
<td>The dying person looks for avenues of immortality as this encounter consists largely of unknown events and an inevitable, but indiscernible outcome. The method of coping may be based on earlier life decisions.</td>
</tr>
<tr>
<td>7. Deciding to slow down or speed up the process</td>
<td>The dying person must decide whether to embrace death and speed the dying process or attempt to slow it down.</td>
</tr>
<tr>
<td>8. Dealing with psycho-social problems which beset the dying individual</td>
<td>The dying patient must look at a future of dependency in a society in which autonomy is prized. He/she may see that, regardless of his/her desires or intent, that he/she may be dependent in a number of areas including housing, finances, personal care and emotional needs. He/she inevitably looses mastery over his/her environment and must adjust to the “sick role” or the “dying role.”</td>
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This concept of hope is retained as a contemporary theme in the works of Sullivan (2003) and Tulsky (2002). Also, in the long-term care setting, residents often have assumed the sick role (Task 8) upon admission; yet, there may be hesitancy or ambiguity to assuming the dying role (Bern-Klug, 2004). For example, the resistance to Hospice enrollment by residents or their families (Schockett, Teno, Miller & Stuart, 2005) illustrates such hesitancy to move from the sick to dying role.

In addition, this theory acknowledges a critical aspect of the dying process, the recognition that one is dying or *awareness of finitude* (Marshall, 1980). It is the awareness of finitude that sets in motion task performance associated with the dying process. Such knowledge may be acquired directly from healthcare providers or by a number of other less direct means (e.g., overheard comments, moving from one care setting to another) and may be incomplete or misunderstood (Kalish, 1979). This theoretical work was seminal in bringing forward themes that continue to resonate and provide substantive areas debated in the current literature. For example, Kalish (along with Glaser and Strauss [1965, 1968]) contributes to the discourse on barriers to communication between medical providers and dying patients that continues to this day (Tulsky, 2002, 2005; Bern-Klug, Gessert, Crenner, Bueaver & Skirchak, 2004).

Also, the expectation of death has proven to be a critical factor in research of the dying process (as noted above) and provision of appropriate care for those who are dying (Munn, Hanson, Zimmerman, Sloane & Mitchell, 2006). Kalish (1979) contemporaries (qualitative researchers Glaser and Strauss [1965, 1968] and notable sociologist Marshall [1980]) initiated this discussion which remains relevant to this day. Finally, there is a
pragmatic sense to the task-based theories that is appropriate in the more applied profession of social work (Turner, 1995).

Corr’s (1992) modification of Kalish’s work seems a bit simplistic. Although still a multi-faceted definition of the dying process (see Table 1.2), there is more complexity in later work than these four categories describe. However, notably, Corr does retain an interactive or dynamic component that is important to understanding death. For example, the physical tasks of satisfying bodily needs and minimizing physical distress are well-documented as components of a good death (Koenig, 2002; Teno, 1999); however, Corr notes that these tasks take place within a value system that varies from person to person. Further, each component of Corr’s typology provides a positive aspect in that each area has a potentially positive outcome.

Table 1.2: Task-Based Areas of Coping with Death and Related Tasks

<table>
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<tr>
<th>AREA</th>
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<td>Physical</td>
<td>To satisfy bodily needs and minimize physical distress, in ways that are consistent with other values.</td>
</tr>
<tr>
<td>Psychological</td>
<td>To maximize psychological security, autonomy, and richness in living.</td>
</tr>
<tr>
<td>Social</td>
<td>To sustain and enhance those interpersonal attachments significant to the person concerned and to address the social implications of dying.</td>
</tr>
<tr>
<td>Spiritual</td>
<td>To identify, develop, or reaffirm sources of spiritual energy and in so doing, foster hope.</td>
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A Conceptual Model

Another way of understanding the end-of-life process is by using an existing conceptual model. Moos & Schafer (1986) developed a model for understanding life crises and trajectories that is particularly appropriate for the work of this dissertation as it can be...
used to examine two important events: (a) admission to long-term care; and (b) the point at which the resident is known to be dying. Both events are transitions which can be perceived as crises (Oleson and Shadrick, 1993). The model is also appropriate for use with the task-based theories as tasks are part of the model itself and Kalish’s (1979) eight tasks are commensurate with the adaptive tasks in the conceptual model. Also, both model and theory place the dying resident in a social context. Further, this model represents an opportunity for social work intervention (see Figure 1.1). As related to end-of-life in long-term care, the first segment of the model, general determinants of outcome, represents individual, family and facility level factors that influence each other and are specific to the resident. For example, personal factors such as cognitive status, ethnic background, and social support influence the resident’s entry into the long-term care system (Vourlekis & Simon, 2006) as well as the experience of dying (Howe & Daratsos, 2006).

Figure 1.1: A Conceptual Model for Coping with Transitions and Life Crises

Also, there are physical and environmental factors (e.g., facility size, for profit-status) that have been shown to affect the provision of care (Zimmerman et al., 2003). Event related factors could include the presentation of the terminal diagnosis (e.g., by a personal physician or someone less familiar to the resident and family) or the indeterminate nature of the dying trajectory. It is important, therefore, that any resident assessment identify such issues.

Within the resolution stage, cognitive appraisal is described as the “perceived meaning of the event” (Oleson & Shadrick, 1993, p. 480). For this population, the cognitive appraisal is that done by family members, guardians, or staff when residents are cognitively impaired and is similar to the precipitating event in task-based theory, awareness of finitude. The adaptive tasks presented in this model, while not identical, are very similar to the tasks presented by Kalish (1979) and Corr (1992). These adaptive tasks include establishing meaning and understanding personal significance (compares to Kalish’s coping effectively with the death encounter); confronting reality and requirements of the precipitating event (similar to Kalish’s contemplating arranging affairs; planning the future); sustaining relationships with family and other supportive persons (Corr’s social area); maintaining a reasonable emotional balance (Kalish’s dealing with psychosocial problems); and preserving a satisfactory self-image and sense of competency (Corr’s psychological area). Consequent coping skills are developed by cognitively intact residents or care providers for residents who are not cognitively intact. According to this model the outcome of a good or bad death would be dependent upon accomplishing the adaptive tasks and utilizing coping skills which are influenced by the general determinants.

While task-based theories (Kalish, 1979; Corr 1992), and the conceptual model (Moos & Schaefer, 1986) are valuable resources for formulating research questions and
designing research studies, further theory testing is needed. For example, researchers must
determine if Kalish’s and/or Corr’s typologies exhaust all aspects of the dying process or
whether there other aspects that are important yet unnamed in stated theory. In addition,
researchers must determine the applicability of this theory to cognitively impaired residents
who are unable to recognize or acknowledge their own impending death. Therefore, utilizing
other theoretical approaches is helpful.

Qualitative Methods

Qualitative methods can provide data that complement stated theory. This dissertation
includes qualitative research methods because little is known about end of life in long-term
care and qualitative methods are especially useful in establishing a base of knowledge
(Padgett, 1998; Patton, 2002). Further, they are particularly appropriate for potentially
sensitive topics and provide an empathetic setting and opportunities for understanding
beyond those available in closed ended interviews and less flexible methodologies. The
observational nature of qualitative research makes this method exceptionally appropriate for
studies of death and dying as the qualitative researcher may be less intrusive and provide
greater empathy (Padgett) while obtaining rich, in-depth data and powerful insight into the
experience of participants (Patton, 2002).

From a methodological view point, this emic perspective (i.e., describing the lived
experience) allows researchers to obtain information inductively, to explore underlying
processes, and to elicit information about potentially sensitive topics (Padgett, 1998; Patton,
2002). In essence, qualitative methods further understanding and make sense of the human
experience (Padgett) and when utilized with skill and rigor, qualitative methods promote the
formulation of research questions and thereby further the research agenda. As a final point,
qualitative data are understandable to both research professionals and laymen, supporting their use to examine topics of interest to a wide range of individuals (Glaser & Strauss, 1967).

*Tradition of Qualitative Methods and Studies of Dying.*

Glaser and Strauss established the utility of qualitative methods and end-of-life research with an ethnographic study of interactions between medical personnel and patients dying in hospital settings (Glaser & Strauss, 1965). This seminal work consisted of four years of intensive field work in six urban hospitals and resulted in a detailed conceptualization of these interactions, *Awareness of Dying* (1965). Glaser and Strauss (1965) described their work as: “substantive theory … that is induced from diverse data gathered over a considerable period of time” (p. 261) [and] corresponds closely to the realities of terminal care” (p. 263).

The tradition of qualitative research methods to describe and evaluate care of the dying continued with Gubrium’s (1975) *Living and Dying at Murray Manor*. This work, a participant observation, contributes a rich sense of place and examines the culture of long-term care. For example, Gubrium gives detailed insight into public and private spaces within a long-term care facility, utilization of space based on resident cognitive status, and development of relationships based on physical proximity and resident cognitive/functional status. (Notably, these themes also naturally emerged in the dissertation focus group study described below).

More recent examples of qualitative research include work by Hanson, Henderson, and Menon (2002), Singer, Martin, and Kelner (1999), Tong, McGraw, Dobihal, Baggish, Cherlin and Bradley (2003). These studies, along with those conducted by Glaser and
Strauss (1965, 1967, 1968) are examples of a complex form of qualitative research known as
grounded theory. The attached paper, *Dying in Long-Term Care: Insights from Residents, Family and Staff*, follows this tradition of qualitative inquiry, specifically using grounded
theory to examine the dying experience and answer the research question: What are the
domains of a good death in long-term care?

*Grounded Theory*

Grounded theory is characterized by the systematic analysis of narrative data
involving open coding (in which the data are fractured), axial coding (in which categories are
related to their subcategories and linked at the level of properties and dimensions) and
selective coding (the process of integrating and refining theory) (Strauss & Corbin, 1998).
Throughout the analytic process, the analyst constantly compares the data to existing codes,
identifies new codes, and asks questions of the data to determine the properties and
dimensions of each category. The analyst also examines the data for latent content,
developing a causal/conditional matrix which allows the researcher to understand the
interactive nature of the data and the conditions under which certain interactions and
consequences occur.

In the dissertation work, the research team utilized grounded theory methods to
examine the data for both manifest and latent content using Strauss and Corbin’s (1998)
methodological process. Initially, the analysts immersed themselves in the data by
transcribing the audio-tapes and reading and re-reading transcripts. This step allowed the
analysts to get a sense of the data. Two members of the research team then coded the
transcripts line by line (open coding using the constant comparative method) independently
and then compared codes, reaching consensus on individual codes. Axial coding created
categories of codes (e.g., Hospice, relationships, circumstances of death) based on the conceptual relationships among the codes (e.g., duration, timing, dying alone were all dimensions of the circumstances of death category). Throughout the process, analysts attached memos to codes, stating hypotheses regarding conceptual relationships as well notations on conditions in which certain interactions occurred. Selective coding and coding for process allowed the analysts to examine for latent content and overarching themes and retained those that emerged as salient in all cases.

For example, during open coding, the analysts developed several codes for relationships. These codes noted relationships between staff and resident, staff and family, resident and family, family and family, and staff and staff. By asking questions about these relationships (who, what, when, where, how), certain properties and dimensions emerged and it became evident that relationships included varying degrees of attachment, reciprocity, empathy and trust. Selective coding led to determination of the central category (i.e., a category that is related to all categories; appears frequently in the data; is abstract; grows in depth and power upon further examination) (Corbin & Strauss, 1998) which, in this study was identified as “closeness.” This central category emerged by creating a conditional/consequential matrix which lead to determination that closeness (based on physical proximity and frequency and regularity of contact among stakeholders) emerged a contextual explanation for the overarching themes. For example, persons who were physically closest and had the highest frequency of contact were the most likely to form relationships. Further, the characteristics of these relationships such as degree of attachment, reciprocity, empathy and trust were a function of the central category.
It is not surprising, then, that family members (who do not live or work at the facility and whose frequency of contact varied) expressed less empathy for other stakeholders and that paraprofessional staff who provided 90% of the care and who had the most frequent and closest contact to residents, developed close attachments to residents, exhibited higher levels of empathy for residents, and identified physical symptoms more accurately than did families or licensed staff. By coding for process (i.e., asking questions about the interactions involved such as: “Under what circumstances did relationships become adversarial?”) the research team found that closeness related to other aspects of relationships as well. For example, staff reported family who had been geographically distant and appeared only at the end-of-life as more troublesome and interfering with care than those who visited regularly throughout the resident’s stay at the facility.

Notably, the methodological steps in grounded theory were not linear. Analysts began to hypothesize about categories of codes (axial coding) while continuing open coding. One overarching theme, the positive association of Hospice with end-of-life care in long-term care reported by all four respondent groups, became evident upon initial reading of the transcripts. Further, as is characteristic of qualitative research, the research moved beyond the initial research question. While the initial research question (“What are the domains of a good death for residents in long-term care?”) was answered, other important and timely themes emerged and those became part of the current manuscript. For example, the Hospice theme evolved naturally (i.e., in absence of direct questions or probes related to Hospice) in all groups and thereby became an essential element of the findings.
As the term grounded theory suggests, theorizing and/or developing theory is the expected outcome of the analyses. In this case, the data supported a theory based on the overarching themes and central category, thus stated:

In long-term care closeness (physical proximity and frequency and regularity of contact) influences the formation of relationships; the properties of those relationships (e.g., collaborative or adversarial; levels of reciprocity, empathy and trust); and the sense of normalcy associated with dying. Higher levels of closeness (i.e., greater frequency and regularity of contact and closer physical proximity) results in the formation of collaborative relationships among residents, family members, and staff which in turn is associated with a good death for residents in long-term care. However, when closeness is less (i.e., less physical proximity and/or infrequent or irregular contact), problems arise that contribute to adversarial relationships and consequently to poor quality of dying or a bad death.

One current typology developed by Sandelowski and Barroso (2003) describes a continuum of complexity for different types of qualitative research. Within this typology, grounded theory fits into the category, interpretive explanation, described as most complex (i.e., with the greatest amount of interpretation and considered farthest from the data) and offering “a coherent model of some phenomenon or a single thesis or line of argument that addresses causality or essence” (p. 914) a definition congruent with the grounded theory methodology described by Corbin and Strauss (1998).

Content Analysis

Unlike grounded theory, content analysis falls into a less complex category, conceptual/thematic description, and is characterized by “imported concepts or themes to
reframe a phenomenon or event” (Sandelowski & Barroso, 2003, p. 913). The dissertation paper, *A Good Death for Residents in Long-Term Care: Family Member Speak*, uses content analysis to examine the comments of family members within the healthcare quality model developed by Donabedian (1966, 1988). This model provides a template of structure/process/outcome which is applied to the participants’ answers to two open-ended questions: “What was done during the last month of life, either by family or staff, that most helped the resident?” and “What could have been done to make that last month better?”

In addition to analyzing the data using the Donabedian healthcare quality model, this paper integrates quantitative methodology as the frequencies of individual codes are one component of the findings. This method fits the data which consist of short statements from individual bereaved family members, and once coded, lend themselves to quantification. Herein lies the essence of choosing among research methodologies: The chosen methodology/tradition must be congruent with the research question. Creswell (1998) indicates that qualitative methods generally answer “what” and “how” research questions; quantitative methods usually answer “why” research questions. Further, the chosen method should reflect the population or materials to be studied (e.g., archived documents vs. live narratives), the pool of available subjects, and the resources on hand (e.g., conducting focus groups often requires more funding than mail-out surveys). Also of paramount importance is the skill and comfort of the researcher with a given methodology (Patton, 2002). The researcher need not wed a particular methodology or tradition, rather the researcher must be thoughtful in choosing the methodology or tradition most appropriate to the research question and other considerations listed above (Creswell, 1998).
In A Good Death for Residents in Long-Term Care: Family Members Speak, the above criteria were met and the overarching research question: “What is important to family members at the end of life for residents dying in long-term care?” was best answered by coding the data qualitatively and then quantitatively analyzing the codes to identify patterns in the responses (Sandelowski, 2001). The software program, Atlas/ti (Berlin) is designed to assist in both processes. Two resounding messages resulted from this work: (a) Families overwhelmingly valued physical presence or “being there” over any other contribution to resident well-being during the last month of life (a variation of the central category, closeness in the focus groups and reminiscent of earlier work by Gubrium [1975]); and (b) one-third of family respondents indicated their perception that nothing could have been done to improve care at the end of life. In addition, it became clear that social workers, the intended audience of the target journal, were scarcely mentioned. These findings would be less evident without quantifying the responses. Further, the findings were interpreted beyond simple quantification and utilized to provide implications for practice (Sandelowki, 2001).

Quantitative Methods

Although qualitative methods are valuable in examining the dying process in long-term care, there are limitations to qualitative methods (e.g., lack of generalizability) that suggest quantitative methods are also helpful. For example, scientifically designed and validated measures of quality at the end of life can contribute to research by providing a benchmark for evaluating interventions to improve quality of care, quality of life and the quality of dying.

Further, there is a conceptual relationship between the domains described in qualitative studies and the factors established in scale development. Indeed, measurement in
the social sciences is the “point at which culture meets science” (M. Fraser, personal communication, class lecture, 2002). That is, measurement instruments are designed to describe an underlying construct (reflective of cultural attributes) using psychometric methods (scientific procedure). Scales, therefore, are collections of items that reveal levels of theoretical variables that cannot readily be observed by direct means. The construct measured by a scale is, therefore, a latent variable (called a domain in qualitative research) which is not constant (that is, the level of the latent construct is a function of other factors). Scale items are the operationalization or the observable manifestations of the underlying construct and would be expected to represent multiple factors which emerge upon psychometric examination (DeVellis, 1991).

The paper, *Measuring the Quality of Dying in Long-Term Care*, describes the development of a measure of the quality of dying in long-term care based on stated theory (Kalish, 1979; Corr, 1992) and prior studies in other settings (Hanson, Henderson, & Menon, 2002; Singer, Martin, & Kelner, 1999; Tong, McGraw, Dobihal, Baggish, Cherlin & Bradley, 2003). The development and testing of a measure concurrent with the qualitative study described in *Dying in Long-Term Care: Insights from Residents, Family Members and Staff* represents a mixed-methods approach to examining a good death with a concurrent triangulated strategy. This strategy is depicted in Figure 1.2. The capital letters of each method indicates that they are equally important. This strategy is used when the researcher seeks to confirm or corroborate the findings (between the two methods) within a single study. Mixed methods offset the weaknesses of one method in utilizing the strengths of the other method. Further, this method, while difficult, can result in well-validated findings and allows for a shorter data collection period (Creswell, 2003). The use of both qualitative and
quantitative methods is a strength of the dissertation and enhances the current value of this work and provides guidance for future research.

Figure 1.2: The Concurrent Triangulation Strategy of Mixed Methods

![Concurrent Triangulation Strategy of Mixed Methods Diagram]

Notes: “+” indicates concurrent data collection; capitalization of both quantitative and indicates equal priority of method.

Contributions to Research

This dissertation, *Defining a Good Death for Residents of Long-Term Care*, reflects the doctoral candidate’s decision to perform research that is meaningful and that translates into practice, thus resulting in enhanced living and dying for vulnerable, older adults who reside in nursing homes and residential care/assisted living facilities. The three papers comprising the dissertation represent a substantial quantity of information and are drawn from three unique data sets which required multiple analyses and two methodological approaches (i.e., qualitative [grounded theory and content analysis] and quantitative [scale development]).
The ten focus groups described in *Dying in Long-Term Care: Insights from Residents, Family Members and Staff*, generated 18 hours of audio tapes resulting in 136 single-spaced pages of typed, narrative transcripts. In addition, descriptive statistics were computed for the 65 respondents. There were 79 pages of data from the open-ended questions analyzed for *A Good Death for Residents in Long-Term Care: Family Members Speak*; quantitative analyses complemented the qualitative component. The quantitative analyses (e.g., exploratory factor analysis) conducted for *Measuring the Quality of Dying in Long-Term Care* involved 677 staff interviews and 451 family interviews. More importantly, these three papers provide important insights into the dying experience in long-term care.

*Dying in Long-Term Care: Insights from Residents, Family Members and Staff*

The focus groups described in *Dying in Long-Term Care: Insights from Residents, Family and Staff* are unique in composition when compared to earlier studies in that they include: (a) four groups of stakeholders (residents, family members, licensed nurses and paraprofessional care providers); (b) both prospective and retrospective viewpoints; and (c) both nursing homes and residential care/assisted living facilities. Therefore, new findings emerged reflecting diversity of viewpoints represented.

For example, residents (prospective and retrospective viewpoints) provided unique insights into themes specific to long-term care (based on physical proximity and frequency of contact) such as the normalcy of death in these settings. In addition, paraprofessional staff caregivers provided insights into the nature of their relationships with family and residents that are often deficient in current literature. By recognizing the importance of all stakeholder views, it became possible to identify areas of consensus as well as areas of difference.
A Good Death for Residents in Long-Term Care: Family Members Speak

The qualitative data in *A Good Death for Residents in Long-Term Care: Family Members Speak*, comes from but one voice; however, it is an important one. Current literature supports the need to recognize family satisfaction with care as a critical measure of the quality of care at the end of life (Teno, 2005; Teno, 1999). This study documents that a significant number (146 out of 437) of family members do not acknowledge the need for improvement in care provision.

This finding raises important questions regarding appropriate standards of care (Donabedian, 1966). Were the family members accepting of care that was perhaps suboptimal because they generally had low expectations or did they make comparisons with the best possible care and found that nothing more could have been done? While these data do not answer that question, they raise the issue for future research. Further, researchers might compare the empirical findings of family expectations with normative standards (i.e., based on established standards within the medical care system). Finally, that families perceive “being there” as the most important contribution at the end of life, has many implications for clinical practice that will be discussed in the dissertation conclusion.

Measuring the Quality of Dying in Long-Term Care

*Measuring the Quality of Dying in Long-Term Care* makes a substantive contribution to research on care at the end of life in the long-term care setting as it introduces an outcome measure of the quality of dying specific to this setting validated on two groups of surrogate respondents (family and staff care providers). This measure enables researchers to examine established domains of a good death and also identifies measurement issues specific to the long-term care setting. For example, respondents consistently had difficulty responding to
items regarding physicians. These data suggest that physicians have less contact with residents, family, and staff in long-term care when compared to other settings and, also, that long-term care residents and families have a unique relationship with the healthcare system characterized by interaction with healthcare providers other than physicians such as licensed nurses and/or nursing assistants. This topic of physician involvement is a timely one and this study confirms findings in other studies (Shield, Wetle, Teno, Miller & Welch, 2005).

However, when these quantitative data are compared with focus group findings (some of which are not included in the current paper), a more subtle issue emerges. Family focus group participants wished to retain personal physicians (rather than one facility-assigned physician who was responsible for all residents) and described better communication with physicians under this arrangement. In contrast, licensed staff reported enhanced communication with physicians when there is one physician (or group of physicians) per facility. This additional perspective allows for more thoughtful research into and evaluation of the physician roles in long-term care: that of providing medical care (i.e., communication with nursing staff) and/or providing medical information and shared decision-making regarding end-of-life issues (i.e., communicating with families and staff). It also suggests roles for social workers in facilitating physician and family communication as discussed in the conclusion to the dissertation.

**Next Steps**

These three studies and resultant manuscripts, while making unique contributions to the current literature on end of life and long-term care, also provide a basis for additional manuscripts as well as a future research agenda.
The depth, quantity, and quality of focus group data support the development of additional manuscripts such as a scholarly article using systems theory and a role theoretical model to examine end-of-life in long-term care or a journal article applying the feminist perspective to the culture of the long-term care industry (e.g., the marginalization of the industry as a whole or the invisibility of residents and paraprofessional care providers within the long-term care culture were latent themes in some of the narratives).

The QOD-LTC, while a promising measure, requires additional validation to determine congruent and/or discriminant validity and will benefit from inclusion of revised items to examine freedom from physical symptoms. That these items did not perform well in this initial version may result from poorly worded items rather than conceptual differences. Therefore, the contribution to research can grow as later versions are differently worded and additional testing accomplished. Integration of findings from the focus groups with the initial QOD-LTC represents an opportunity for further scale development. For example, the focus groups confirmed the importance of the domains of a good death described in the QOD-LTC. However, there were emerging themes that suggest additional item development (e.g., circumstances of death) along with new items to measure physical symptoms.

There have also been advancements in the state of the science since the original QOD-LTC items were developed. These advancements, such as National Consensus Project (NCP) Clinical Practice Guidelines (identifying eight domains of care) and other conceptual models can guide efforts toward a more comprehensive measure (Ferrell, 2005). For example, there is a need for items related to cultural sensitivity as an aspect of a good death, a domain included in the NCP guidelines. However, the particularities of dying in long-term care (e.g., the close proximity of residents to others who are dying; the unique composition of
the care staff) need not be subrogated to these more general models and new items should reflect this unique setting of care.

In conclusion, there remain many challenges to end-of-life research conducted in long-term care settings. However, due to the importance of this topic, researchers need to utilize existing resources such as stated theory, conceptual frameworks, grounded theory, end-of-life research conducted in other settings, and the studies that comprise this dissertation to move forward.
CHAPTER 2
DYING IN LONG-TERM CARE: INSIGHTS FROM RESIDENTS, FAMILY MEMBERS AND STAFF

Introduction

Almost one quarter (24%) of older adults in the United States die in long-term care (LTC) settings (Temkin-Greener & Mukamel, 2002). Mortality rates range from 14-22% in residential care/assisted living (RC/AL) facilities (Golant, 2004; Zimmerman, Sloane, Eckert, et al., 2005) to 34% during the first year of residence in nursing homes (NHs) and 24% thereafter (Keily & Flacker, 2003). Based on demographics estimates, experts indicate that LTC settings will continue to be sites of death for many older adults (Teno, 2002). However, little is known about the EOL experience in LTC.

One approach to examining this important issue is using qualitative research as it aids in establishing a knowledge base in substantive areas in which little is known. Further, these methods are particularly appropriate in areas related to sensitive topics as they provide an empathetic setting and opportunities for understanding beyond those available in closed ended interviews and less flexible methodologies (Padgett, 1998). Some recent studies have used qualitative methods such as focus groups and interviews to determine what is important at the end of life (EOL) (Emanuel & Emanuel, 1998; Singer, Martin, & Keller, 1999; Steinhauser, Christakis, Clipp et al., 2000; Patrick, Engelbert & Curtis, 2001; Tong, McGraw, Dohihal et al., 2003). These studies have incorporated input from a variety of respondent groups including seriously ill patients, bereaved family members, and
professional caregivers such as social workers, physicians, nurses. In this work, areas of importance that emerge include pain and symptom management, alleviating burden placed on loved ones, social relationships and support, spirituality, being treated as a whole person, and avoiding prolongation of the dying process. Notably, none of these studies was specific to death in LTC and only one study (Singer, Martin & Keller, 1999) included LTC residents among respondents. This is an important omission as the setting of care influences many aspects of the dying experience including care philosophy, available services, relationships with care givers as well as caregiver training and knowledge (Mezey, Dubler, Mitty & Brody, 2002).

Therefore, research, especially qualitative research, specific to LTC is needed to determine what is important at the EOL. These studies should examine issues beyond medical care and symptom management such as spirituality and social support (Kayser-Jones, 2002) and the depersonalization of dying (Sulmasy, 2002). Further, in lieu of expert opinion, research studies should seek population-level information on quality of EOL care from residents, staff, or their families (Clark, 2003; Singer & Wolfson, 2003; Teno, 1999). Each of these respondent groups offers a unique and meaningful perspective on what is important at the EOL for LTC residents.

This study consisted of ten focus groups and is unique in including four groups of stakeholders: residents, family, paraprofessional care providers and licensed staff (in homogenous groups). The initial study aim was to determine the domains of a good death in LTC based on input from all four stakeholder groups and to confirm/disconfirm the domains identified in other settings. However, as the study progressed, focus group participants provided depth and insight on a variety of issues that were related to the EOL yet went
beyond the good death definition. Therefore, based on the principal of theoretical sampling (Corbin & Strauss, 1998), the study aims were expanded to include an examination the EOL experience in LTC, the development of a set of overarching themes, and grounded theory to integrate those themes.

Method and Design

Ten focus groups were conducted which were homogeneous in composition and comprised of: LTC residents (two groups); family caregivers of decedents who died in LTC (two groups); LTC paraprofessional staff caregivers (three groups); and LTC licensed staff caregivers (three groups). A trained facilitator conducted each group using a semi-structured interview guide. Each group was audio taped and notes recorded. All groups were conducted in private rooms, with one group held at a senior center and the others in restaurants. Following the theoretical sampling model (Glaser, 1994), one of each type of group was conducted, the transcript reviewed, and modifications to the interview guide made, in consultation with the group facilitator, before conducting the second group of that type. Group sizes ranged from 3 to 12 participants.

Participants

Participants were a purposive (based on geographic proximity) sample (n = 65) of residents (n = 11); family members of decedents (n = 19); paraprofessional staff (n = 20), and licensed staff (n = 15), (drawn from 13 North Carolina facilities which participated in the NIH-funded parent study, *End of Life in Nursing Homes and Assisted Living Facilities*, Sheryl Zimmerman, PI). In this study, staff and family provided data on the EOL experience of decedents. In the focus group study, it was desirable to elicit their open-ended perspectives of what they considered important and allow new themes to emerge. Prior to contacting
potential participants, the project coordinator sent each facility administrator a letter describing the focus group study and then called the administrator, requesting permission to contact facility staff who had participated in the parent study. All facility administrators agreed that the research team could contact facility staff.

General

Prior to beginning each focus group, the project coordinator reviewed the consent form and procedure (e.g., voluntary nature of participation, confidentiality of the focus group discussion, payment for participation) and each participant (except for residents whose consent was obtained in person prior to group attendance) signed a confidentiality agreement and consent form. Demographic data (e.g., age, gender, race) were obtained for each participant. In addition, each participant received a meal and a $25 token of appreciation. Resident participants were transported to and from the focus group location. All procedures were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Staff

Upon receiving facility consent, the project coordinator contacted first by letter and then by phone all staff who had participated in the parent study and were still employed by participating facilities. However, there were too few such individuals to compose groups within geographic areas, and so to assure sufficient numbers of staff participants, additional snowball sampling was employed. Staff were asked to identify others who might be interested in participating. After the referring person had received permission from the potential participant, the project coordinator contacted potential participants by phone, described the study, and obtained verbal consent.
**Family Members**

Upon obtaining facility consent, the project coordinator sent a letter describing the study to family members who had participated in the parent project and lived within the Triangle area of North Carolina. The project coordinator then called each family member and obtained verbal consent for participation. The procedure at the focus group meeting was the same as for staff.

**Residents**

The project coordinator contacted three of the 13 participating facilities (one NH and two RC/ALs) to request names of residents who might participate in a focus group on the EOL experience. Criteria for participation included the ability to transfer to and from a specially equipped van necessary for transport to the focus group location (wheel chair occupants were eligible), to verbally participate in a focus group conducted in English (i.e., mild to moderate hearing and cognitive impairment were acceptable), and willingness and ability to discuss a sensitive subject without undue stress. The study coordinator then went to the facility and met with each resident candidate, described the study and obtained informed consent.

**Measures**

The facilitator used a semi-structured interview guide with four primary questions: (a) “Some people have talked about the differences between a ‘good death’ and a ‘bad death’ in long-term care. What does this mean to you, based on your experience?”; (b) “If you could change (or control) only one thing at the EOL, what would it be?”; (c) “What other aspects of residents’ deaths do you feel are particularly important?”; and (d) “Is there anything you would like to add?” Further, the facilitator (using the guide) elicited and probed new areas
mentioned by the participants, in accordance with standard focus group conduct allowing naturally occurring themes to emerge.

Data Entry and Analysis

The research team transcribed the focus group recordings verbatim, entered the data into Atlas/ti (Scientific Software, Berlin) and examined for the data for both manifest and latent content. Initially, two coders analyzed each transcript independently for manifest content using the constant comparative method, open coding, and attaching memos to each code (Glaser & Strauss, 1967). The analysts then met and reached consensus on each code. After coding one group of each type, the analysts compiled a master list of 107 codes for use in coding additional transcripts; however, additional codes were allowed to emerge and axial coding employed to develop conceptual relationships among codes (Strauss & Corbin, 1998).

Following manifest coding, three members of the research staff analyzed the manuscripts for latent themes by reading one of each type of manuscript simultaneously, asking questions of the coded data, and identifying themes as they emerged. Research staff also used selective and theoretical coding and examined the interactions that took place to examine the circumstances in which the interactions took place. Further, the research staff examined the dimensions and properties of each theme and used these themes to code the remaining transcripts. Themes that were relevant to all cases (i.e., occurred in each of the ten groups) were identified as overarching themes and a central category identified following selective coding (Strauss & Corbin, 1998). Demographic data were entered into SPSS 13 (SPSS, Inc, Chicago, Illinois).
Results

Resident participants (n = 11) were white (82%) and female (64%), with a mean age of 79 years old (SD = 9) (see Table 2.1). Approximately half (46%) had less than a high school education and an equal proportion (45%) had some college or greater. Almost half (46%) were widowed. Family caregivers (n = 19) were predominantly white (84%) and female (90%) with a mean age of 54 years old (SD = 10). Almost three-quarters (74%) had a college education or higher and almost half (47%) were married. Fifteen (79%) were daughters or daughters-in-law of the decedent; two were sons, one was a spouse, and one was a sibling. Approximately half (45%) of the paraprofessional staff (n = 20) were white and half were black (45%) with a mean age of 46 years old (SD = 11). One quarter (25%) had high school education; 40% had some college or trade school training, and 10% were college graduates. Licensed staff (n = 15) were also predominantly female (93%) and almost half (47%) were white, approximately one-third (33%) were black, and 20% other with a mean age of 36 years old (SD = 10). Almost three-quarters (73%) had some college or trade school training and over one-quarter (27%) were college graduates.

There were eight overarching themes that emerged in all groups (See Table 2). Some resulted from the questions posed by the facilitator (e.g., the domains of a good death); others evolved naturally (e.g., Hospice and the normalcy of death).

Theme 1: The Basic Components of a Good Death were: Physical Symptom Management; Circumstances of Death; Preparation and Closure; Spirituality; Dignity; and Family Burden.

Respondent groups provided similar definitions of a good death. Several themes emerged that had been identified in similar studies conducted in other settings. All
respondent groups contained themes of physical symptom management (e.g., “being kept comfortable’); circumstances of death (e.g., short in duration, not “hanging on and hanging on;” “not hooked up to machines;” and “surrounded by family”); preparation (e.g., “having things in order”) and closure (e.g., acceptance of death and giving permission to die); spirituality (e.g., “God here I am. Go ahead and do what you need to do”); dignity (e.g., attentiveness to issues of incontinence); and family burden (e.g., relieving family burden was a motivation for moving into LTC) as important at the EOL.

**Theme 2: There is a Sense of Normalcy Associated with Dying in LTC for Some Respondents**

The normalcy of death in LTC was a naturally evolving theme among the respondent groups who were consistently and frequently within the facility. That is, the residents, paraprofessional staff, and licensed staff had socially constructed definitions of normalcy based on experience and expectation related to the frequency of death and the physical proximity to other residents who were dying. For most, but not all, death was an expected outcome of moving into LTC. However, few family members expressed a sense of normalcy regarding dying in LTC. Those who did had prior experience with death in other settings or with deaths of other family members who had died in LTC.

The matter of frequency was initiated by an 84-year old, male RC/AL resident: “One thing that hasn’t been mentioned, we, I don’t want to say we are surrounded by death, but for 350 people, elderly people, death is not unusual.” Further, he and other group members considered three deaths within one month as normal; more than three prompted a response of “Wow.” Conversely, paraprofessional staff from another facility became upset when that facility experienced six deaths in a three month period. In both cases, participants noted the deviation from some expected frequency as noteworthy, although the expected frequency of
death was quite different in the two facilities. In a similar way, paraprofessional staff had become familiar with death and considered it normal. A 34-year old nursing assistant described how staff, sometimes incorrectly, anticipated death: “When they’re sick you can almost guess or estimate when [THEY WILL DIE]. Usually they die in threes. And all the residents know that too. When one dies, they’re thinking I wonder who’s sick. Who’s going to go next? And then, somebody else passes. Somebody who’s been walking around all day and they just drop.”

The matter of proximity related to normalcy in that due to living in close proximity to one another, residents became accidental witnesses to the deaths of other residents and described direct involvement, voluntary or involuntary, in these occurrences. An RC/AL resident described: “And I was in an apartment in which the gentleman on the other side of the curtain was at the end of life and three times they came in and asked me if I would not like to move and … I did say no… I began to realize that I should have [MOVED] when the priest came in and was saying the last rights for the gentleman.”

Also, residents happened upon other residents who were dying and willingly became part of the dying experience. An 87-year old resident with a background in healthcare indicated: “And I was with one person at [FACILITY NAME], who died...she had friends in the room with her all the time, morning, noon and night. All the time she was dying, she had friends and I happened to go into the room at the point when she was really dying. And it was so fine that they allowed that, her friends were in the room all the time.”

Resident participants in both groups had observed the removal of deceased residents’ bodies from facilities. In one NH facility, bodies were taken through the main lobby; in another, the morticians came and left by the freight elevator. Residents considered both
practices undignified. In other facilities, staff made sure residents did not witness this event by closing doors and removing residents from hallways. Residents saw this practice as representing dignity and respect for the decedent, as did some staff. However, other staff felt that this practice was unnecessary and that residents recognized the normalcy of death more readily when it was openly acknowledged.

*Theme 3: Relationships are Instrumental in the Provision and Receipt of Care*

All four respondent groups described relationships as instrumental in delivery and receipt of care. Residents established relationships with facility staff in order to negotiate care delivery. Some nurtured relationships with direct care staff; others established a relationship with the facility administrator. When things did not go well, they relied on these relationships to help them rectify problems: one 71-year old male resident indicated that he “went straight to the top” with problems. Family members also saw relationships as a method of assuring better quality of care. The daughter of a NH resident described: “I found that having relationships with people was the most important thing. And I worked really hard at that. And it would kill me when people would turn over. The unit nurse was probably the most important person.” Relationships also were important to staff. An experienced nursing assistant stated: “I’m really attached to our residents. I’m attached to every single one of them. I know what they like; I know what they don’t like.” Another stated: “You can’t help but care. If you don’t care, there was no way that you can do this job.” Notably, staff also reported having been trained not to establish relationships with residents. Yet they consistently chose to ignore this training and saw relationships with residents as essential to doing their jobs.

*Theme 4: Relationships in Long-Term Care are Complex*
The delineation between professional and personal relationships was blurred in the LTC setting. Participants often described relationships as family-like when describing relationships between staff and residents, between staff and families, and among staff. One licensed nurse said: “You do and you’re caring for them and you’re making them comfortable and it’s just like a family member because that’s the way I look at it.” Staff also saw themselves as replacement family for residents who did not have family nearby. They sat with dying residents, often on their own time. One licensed nurse stated: “Working at [FACILITY NAME], there are many people who don’t have friends and family come visit them. So the staff becomes their family. So even if it is just a staff member who is there at the time of passing, they know that somebody is there for them, somebody who cares about them.” Further, staff expressed family-like grief and bereavement, as a paraprofessional from an RC/AL facility described: “They also encourage us to go to the funerals, go to the memorial services that the families are having. If we were really close to a resident we’re like family too. We’re just family in a different part of their life.” Another described sibling rivalry: “You’re there with them 24/7 and you know more than the family member knows. They don’t like it like that.”

Staff, both paraprofessional and licensed, provided emotional and spiritual support to residents in addition to personal and medical care. They indicated that they prayed and sang with and for dying residents, sometimes openly and at other times privately. Further, some staff saw themselves as responsible for family emotional and spiritual support as well. This was evident in the following description from a nursing assistant in a dementia care unit of an RC/AL facility: "...making them [FAMILY] feel that it’s okay; it’s okay to cry, it’s okay to touch them, it’s okay to talk to them because they still hear you. I had a resident’s daughter
who wanted me to sit next to him and I said:  ‘You sit here; this is your daddy. Talk to him. Let him know you’re here…I’ll step out.’ …for us to be there for the family members as much as we possibly can, that’s important to me because I’ve taken care of that loved one and I want to take care of that family member also.” However, family members associated with these same facilities did not report receiving emotional and spiritual support from staff. When asked about spiritual support one family member responded:  “Are you out of your mind? I’m sorry but they were not, no, I’m mean, you know, I had to go and find a social worker …There’s no communication. No, I would say there was no spiritual, emotional help.”  Paraprofessional staff provided emotional and spiritual support to one another. As one nursing assistant described:  “I know that the two aids that work in the unit with me if somebody was to be dying or anything, they would cover the rest of my residents and theirs … so we know to cover them and to give them an hour, whatever they need if they want to sit with that resident.”

**Theme 5: Relationships Varied in Degrees of Reciprocity, Empathy, and Trust.**

Residents demonstrated empathy and reciprocity in relationships with staff, expressing concerns for them and their families with one 87-year old, female NH resident remarking:  “Of course, they’re people. They have their own lives.”  Both paraprofessional and licensed staff expressed and demonstrated empathy for residents and their families in spite of unpleasant resident characteristics as a nurse reported:  “I even miss the people that I don’t like because …you become attached to them.”  Families were less likely to express empathy for staff, although one daughter indicated:  “I wouldn’t do that job for all the tea in China and for minimum wage. I think they do a really good job. My mother …said:  ‘You know, if I had to be incarcerated, I think I lucked out.’”
There were notable variations in empathy and emotional closeness between family members and deceased residents. It was not unusual for family members to personalize the death from their perspective, relating questions to themselves, rather than the resident (e.g., commenting on how the decedent’s death fit into the flow of the family). One family member indicated: “I was not there when my mother died...we buried her in Ohio, not here. So, I had a lot of other things to take care of here to be able to get her up there and get the funeral things up there too.” Although one family member expressed empathy for her mother who was unable to verbalize her need, there were fewer expressions of empathy toward deceased residents in family groups than staff groups.

Family members and residents described varying levels of trust toward facilities and facility staff. Family members expressed the greatest distrust. Further, family members demonstrated their distrust; they described showing up at the facility at different times so staff would not know when they were coming. They also expressed concerns about retribution toward residents if they expressed complaints too aggressively. Residents were more trusting and expressed trust in the facility to provide appropriate care; however, they also expressed distrust in the direct care staff whom they accused of stealing.

Theme 6: Relationships Became Adversarial under Predictable Circumstances

Family and staff described circumstances that created conflict and caused family/staff or resident/staff relationships to become adversarial. These circumstances were perceived differently by different stakeholders.

Conflict at the EOL. Relationships between family and staff became adversarial when staff saw family as interfering with appropriate EOL care. This conversation occurred among licensed staff: (Speaker 1) “I’ve had residents that nobody has seen them for ten years but
when you called them up and told them something that happened they” (Speaker 2) “come out the woodworks!” (Speaker 1) “and they want you to do everything at the last minute.” (Speaker 2) “They really have to compensate …And it seems like you know the attention is taken off the resident who the attention should be given to and the family member just consumes all the attention.” Another licensed nurse stated: “Families can help or hinder. If the family member has a grudge…I’ve had to assist family members out of rooms. Some of the families never come and visit and they just want to be there on the end, so instead of peaceful time, it becomes very high anxiety.”

**Miscommunication.** Relationships became adversarial when there was miscommunication between facility staff and families, especially regarding medical treatment and the timing and expectation of impending death. Some miscommunication was as simple as word choice. For instance one family member explained: “The lady told that my mother-in-law had expired. Well, the only time I had ever heard expired was like your credit card expired. I have never heard you use that term pertaining to a human being.” All focus groups emphasized a desire for truth in communication and when miscommunication occurred, families consistently perceived this as staff being untruthful. Family members assumed that the staff could accurately predict the time and circumstances of death and expressed great distress if staff had not notified them of an impending death: “I was devastated that I had not been there with her. And I feel that she would have been devastated as well and in all of my life, the one thing she was afraid of was dying alone and she died alone.”

**Theme 7: Hospice Made a Positive Contribution to Care at the EOL**
The Hospice theme evolved naturally in all focus groups and all four respondent groups indicated that Hospice services made a positive contribution to care at the EOL in LTC. However, each group perceived the function of Hospice differently. Residents, some of whom had been enrolled in Hospice, indicated that Hospice contributed to their personal outlook on dying, saying: “And that’s where Hospice sets in or steps in and helps you understand what death’s about and you have a different outlook on it when someone tells you and you don’t dwell on it every day or every week and you have an understanding with your family.”

Families primarily saw Hospice as a way of monitoring care. One daughter stated: “So, for me having Hospice was having another set of eyes. If they did nothing else, I could call them and talk to them and say, what did you see?…It was just that sense that at least I knew that there was somebody else that I could rely on to just be there, to just let me know if something was going on, to be just that extra set of eyes that was needed.”

Licensed staff saw Hospice as experts in pain management, sources of training and bereavement services for staff, in addition to providing services to families. Paraprofessional staff indicated Hospice provided additional care: “Any questions that come up, the Hospice that we deal with is very, they’re very assertive …when you call them, you get a response;” however, they did perceive some communication problems between paraprofessional staff and Hospice workers: “The Hospice nurses come in and they talk to the DON and ADON and they figure out what their role’s going to be, what kind of medication they’re going to give them. But they don’t include us on how we’ve been taking care of this patient for like two weeks or whatever. I think they should include the CNA.”

*Theme 8: Recommendations for Improving Care at the End of Life*
Focus group participants stated two recommendations regarding improving care at the EOL: the need for more, trained direct care staff and the need for social work involvement. These recommendations were not explicitly solicited. Rather, they emerged from general questions regarding how EOL care might be improved. All respondent groups commented on the need for additional staff. One licensed nurse stated what was most important to her was: “Having the staff to provide the care. Everybody knows there is a nursing shortage. When we’re at our end of life, there are not going to be anybody to take care of us.” A family member indicated: “they need to take that money and pay their staff nurses because I believe they should quit burning out their nurses.” Residents also indicated the need for more staff and consistent staffing patterns: “Well, they don’t have enough CNAs and they have a great big turnover…you get acquainted with the CNAs and the first thing you know, they’re gone.”

Participants also indicated a need for greater social work involvement, especially with families. As one licensed nurse described: “A major problem I see is when somebody is dying or near their end of life social services is not involved enough. It’s very minimal. For them to be involved and help the family …to be able to deal and cope with a resident dying, what they are going through …social service are not working with them much and they very rarely see them and they just sort of know hearsay about what is going on.” However, she also recognized staffing constraints, having worked in a facility in which there were 380 patients and one social worker.

**Grounded Theory**

Selective coding led to determination of the central category (i.e., a category that is related to all categories; appears frequently in the data; is abstract; grows in depth and power upon further examination) (Corbin & Strauss, 1998) which, in this study was identified as
“closeness” (based on physical proximity and frequency and regularity of contact among stakeholders) emerged as an integrating context for the overarching themes. For example, persons who were physically closest and had the highest frequency of contact were the most likely to form relationships. Closeness also influenced the properties of those relationships (e.g., collaborative or adversarial; levels of reciprocity, empathy and trust); and the sense of normalcy associated with dying. When there is less closeness (i.e., less physical proximity and/or infrequent or irregular contact), problems arise that lead to adversarial relationships and consequently to poor quality of dying or a bad death.

Discussion

This study set out to examine the components of a good death in LTC. However, the use of qualitative methods enabled the research team to move beyond this initial aim and capture other themes that arose during focus group conduct and data analysis. Also, although focus group participants identify essentially the same components of a good death as in studies conducted in other settings, these additional themes reflect the uniqueness of living and dying in LTC. Underlying these themes is one central category, a sense of closeness: that is residents who live in LTC settings and staff who work there are in close physical proximity to one another and have frequent and regular contact. This sense of closeness affects how they live their lives and also their experiences with death and dying. On the other hand, family members generally are more distant and have less frequent or irregular contact with other stakeholders. This sense of closeness (or distance in the case of some family members) provides the context for understanding the focus group findings.

Frequency of contact and physical proximity are especially pertinent in the theme of normalcy of dying in LTC. For three of the four respondent groups, there is an overall
expectation of death as part of the LTC setting. Despite higher mortality rates in NHs, residents of both RC/AL facilities and NHs see death as normal (Kiely & Flacker, 2003). However, LTC residents did not wish to dwell on death. They accepted death as normal, but preferred to focus on life and living, confirming findings in other studies (Engle, 1998; Engle, Fox-Hill & Graney, 1998).

This study also confirms findings from other studies that developing and maintaining relationships have positive effects on resident quality of care, quality of life, and quality of dying in LTC (McGilton, 2002; Zimmerman, Sloane, Hanson, Mitchell, & Shy, 2003); however, these study findings go beyond resident/staff relationships to examine family/staff, family/resident and staff/staff relationships. This more nuanced examination reveals relationships that are complex and varied. For example, it seems counterintuitive that family members would express less empathy for residents than expressed by licensed staff and paraprofessional care providers; however, this was consistently the case. When examined in the context of closeness, this finding becomes more understandable as family members have less physical proximity and less contact with residents (Port, et al., 2003) than staff. Residents also described feelings of empathy for staff and concerns regarding family that suggests a level of reciprocity in resident/staff relationships which has not been noted in existing literature.

Although staff expressed empathy for both residents and family members, family seldom expressed empathy for or understanding of staff. These findings are congruent with current literature which describes Staff/family relationships as adversarial and characterized by stereotyping, distrust (Krause, Grant, & Long, 1999; Tobin, 1995), unrealistic expectations (George & Maddox, 1989; Heiselman & Noelker, 1991), anger, and annoyance.
(Foner, 1995; Vinton & Mazza, 1994). The issue of trust emerged as particularly salient in describing family/staff relationships. Other studies report that poor communication, resulting from time pressure, fears of retribution, and socio-economic differences contribute to the stress in relationships between family and staff (Pillemer, 1996). On a more hopeful note, interventions to overcome barriers to communication, although infrequent, have shown promising results (Pillemer, 2003).

**Limitations**

This study had several limitations worth noting. As with all qualitative studies, the findings cannot be widely generalized. However, the study represents four distinct participant groups from 13 facilities and allows for triangulation of sources. The inclusion of 65 participants in 10 focus groups is robust in terms of qualitative standards.

Another limitation is that participants in focus groups may not be representative of others involved in LTC. It is possible that licensed and paraprofessional staff focus group participants would be highly motivated and that family members who had strong opinions would attend. Resident attendance was dependent upon certain physical factors such as hearing and cognitive status. Although these populations may not be representative, there is value in learning from the best staff and most opinionated families in order to develop interventions that are worthwhile. Further, these groups occurred between 6 months and 2 years post-death which may have affected the ability of families to recall details accurately.

**Implications for Policy**

As Hospice involvement is viewed positively, barriers to Hospice utilization need to be addressed. Currently, there are regulatory and financial barriers to utilization of Hospice in LTC, especially NHs. Regulatory guidelines prohibit allowing a resident to decline
without intervention to cure the resident (Meier & Morrison, 1999). Financial barriers are known to limit the provision of Hospice care for NH residents who are receiving Medicare skilled services (Zerzan, Stearns & Hanson, 2000). Some of these include lower reimbursement rates and delayed reimbursement for dually-eligible Medicaid/Medicare Hospice beneficiaries (Miller & Mor, 2004). Also, NH administrators may discourage Medicare Hospice enrollment for those who qualify for Medicare Skilled Nursing Facility (SNF) coverage and are dually-eligible because Medicare's SNF benefit has a higher room and board payment rate than the typical Medicaid NH benefit (Gage, et al., 2000). Policies to provide equivalent funding for Medicare Hospice beneficiaries and elimination of the provision requiring a six-month terminal diagnosis for Hospice enrollment are needed to promote Hospice usage in LTC.

Implications for Facility Practices

Staff focus group participants expressed high levels of investment in EOL care for dying, a perspective supported by earlier studies (Zimmerman, Sloane, Hanson, Mitchell & Shy, 2003). In addition, staff participants expressed empathy for residents, family members and other staff. Attachment, empathy and concern for residents are essential but often overlooked attributes of outstanding care staff (Karner, Montgomery, Dobbs & Wittmaier, 1998). In fact, staff reported being trained not to become attached to residents, but saw this attachment as an essential component of the care giving process. Facilities should provide additional personnel to allow staff to stay with dying residents and their families while maintaining appropriate care for other residents. Recognizing that staff consider themselves family of residents (Ersek & Wilson, 2003), these data also suggest that staff receive bereavement services and attend funeral or memorial services.
Initiatives to improve EOL care in these settings should support practices that foster
closeness, collaboration, and therefore enhanced care for older adults who live and die in
LTC. Unfortunately, social workers, who are trained in fostering collaboration and mediating
adverse relationships, were noticeably absent in the reports of focus group participants or
were mentioned as providing inadequate services. At the time of admission, social workers
can initiate discussions facilitating shared decision-making, a hallmark of effective EOL care
(Csikai & Chaitin; Teno, 1999). Social workers also can intervene when relationships
become adversarial. This involvement of social workers would contribute to collaboration
among stakeholders and thereby enhance the EOL experience for those dying in LTC. In fact,
EOL is seen as a significant opportunity for social work involvement (Csikai & Chaitin,
2006) and studies indicate social work involvement has improved EOL care in other settings
(Cobbs, 2001). Currently, there are standards of practice (NASW, 2004) and education
modules for social worker EOL training (e.g., The Social Work End-of-Life Project) (Christ,
2005).
Table 2.1: Respondent Characteristics by Respondent Groups

<table>
<thead>
<tr>
<th></th>
<th>Residents (n = 11)(^a)</th>
<th>Family Caregivers (n = 19)(^a)</th>
<th>Paraprofessional Staff Caregivers (n = 20)(^b)</th>
<th>Licensed Staff Caregivers (n = 15)(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>N (%)</td>
<td>Mean (SD)</td>
<td>N (%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>79 (9)</td>
<td></td>
<td>54 (10)</td>
<td>46 (11)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td></td>
<td>7 (64)</td>
<td>17 (90)</td>
<td>19 (95)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
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<td>11 (100)</td>
<td>17 (90)</td>
<td>17 (85)</td>
</tr>
<tr>
<td>Non-Hispanic</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Race</strong></td>
<td></td>
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<td>16 (84)</td>
<td>9 (45)</td>
</tr>
<tr>
<td>White</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>2 (18)</td>
<td>2 (11)</td>
<td>9 (45)</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Other</td>
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<td>1 (5)</td>
<td>1 (5)</td>
<td>3 (20)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td>5 (46)</td>
<td>0 (0)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>&lt; High school</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>1 (9)</td>
<td>1 (5)</td>
<td>5 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Some college/trade school</td>
<td>1 (9)</td>
<td>4 (210)</td>
<td>8 (40)</td>
<td>11 (73)</td>
</tr>
<tr>
<td>College +</td>
<td>4 (36)</td>
<td>14 (74)</td>
<td>2 (10)</td>
<td>4 (27)</td>
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<tr>
<td><strong>Marital status</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>2 (18)</td>
<td>2 (11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
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<td>9 (47)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
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<td>3 (16)</td>
<td></td>
<td></td>
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<tr>
<td>Separated</td>
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<td>1 (5)</td>
<td></td>
<td></td>
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<tr>
<td>Divorced</td>
<td>2 (18)</td>
<td>3 (16)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) Two groups, \(^b\) Three groups
Table 2.2: Overarching Themes

1. The basic components of a good death are similar to those identified in other settings.
2. There is a sense of normalcy associated with dying in long-term care for some respondents.
3. Relationships are instrumental in the provision and receipt of care.
4. Relationships in long-term care are complex.
5. Relationships varied in degrees of reciprocity, empathy, and trust.
6. Relationships became adversarial under predictable circumstances.
   a. Conflict between family and staff over end-of-life care
   b. Miscommunication between family and staff.
7. Hospice made a positive contribution to care at the end of life.
8. Participants made recommendations for improving care at the end of life:
   a. Increased staffing levels for direct care staff.
   b. Increased social work involvement.

\(^{a}\) Themes that occurred at least once in each focus group.
CHAPTER 3

A GOOD DEATH FOR RESIDENTS OF LONG-TERM CARE: FAMILY MEMBERS SPEAK

Introduction

Escalating longevity with consequent longer periods of dependency and multiple family caregiving burdens have led to greater use of residential long-term care and professional caregivers for frail elders. Consequently, more than 1.5 million persons over the age of 65 live in nursing homes (NHs) in the United States (US Department of Health and Human Services, 2003). Many of those who enter typically do not leave, with up to two thirds of NH residents dying there rather than in hospitals or private homes (Hanson, Henderson, & Rogman, 1999). Annual mortality rates for this population are as high as 34% during the first year of residence and 24% thereafter (Kiely & Flacker, 2003). Another notable site of death gaining recognition are residential care/assisted living (RC/AL) facilities. This supportive environment houses approximately one million older adults who evidence mortality rates of 14-22% annually (Golant, 2004; Zimmerman, et al., 2005). Overall, the proportion of US deaths occurring in long-term care is 23% (Facts on Dying, 2004), and is expected to increase to 40% by the year 2040 (Brock & Foley, 1998; Teno, 2002). In addition, 30% of Medicare recipients who die in hospitals are recent transfers from long-term care facilities, often dying within 72 hours of admission (Smith, Kellerman, & Brown, 1995). Further, provision of Hospice care within these settings is idiosyncratic, with usage rates ranging from 5% to 20% and varying across geographic areas (Miller, et al.,
2004; Miller & Mor, 2001). Thus, these statistics indicate that care of the dying is common in long-term care facilities and that this care is most often provided by facility personnel.

Definitions of a Good Death

Defining a good death is not a new topic. Not surprisingly, its origin predates empirical research and has religious roots. Numerous Old Testament references describe a good death as “full of years” and “in a ripe old age” (Greshake, 1974). Pacific societies also equate death in old age with a good death (Counts & Counts, 1985). However, until the twentieth century, death in old age was uncommon. People typically died from accidents, illnesses, and unknown causes long before reaching the status of senior citizen. Then, in the twentieth century, death became the province of older people (Marshall, 1980) and the assurance of a good death became the responsibility of those caring for them.

In the United States, focus on a “good” death emerged as an issue in medical and social sciences approximately 35 years ago. It appears to have grown out of the institutionalization of the Hospice movement that began in the United Kingdom (Patrick, Engelburg & Curtis, 2001). This movement defines a good death as one marked by “…dignity, tranquility, and comfort, taking place at home, surrounded by loving kin” (Asch-Goodkin, 2000). Another consensus definition of a good death is based on adhering to the dying person’s preferences for treatment and circumstances of death (Patrick et al., 2001). However, while dignity, tranquility, and respecting treatment preferences are worthy goals in any setting, for residents who die in long-term care, a good death is highly dependent upon the quality of care provided.
**Quality of Care**

The definition of quality of care has evolved over time and was initially described exclusively in medical terms. The patient was viewed as a problem to be solved and care was evaluated solely as the alleviation of physical distress. Later, the medical model was challenged by a whole person concept (Sulmasy, 2002) and Donabedian’s (1966) work, indicating that achieving health and satisfaction should be the ultimate quality indicator. More recently, biopsychosocial and ecological models have been advanced (Engel, 1977; White, Williams, & Greenburg, 1996) which are patient-centered and consider attention to psychological and social needs such as relationships as central. In 1990, the Institute of Medicine defined quality of care as the degree to which health services “increase the likelihood of the desired health outcomes and are consistent with the current professional knowledge” (IOM, 1990, p.21). However, none of these models addresses end-of-life care specifically (Sulmasy, 2002).

Initially, concepts regarding end-of-life care (and more specifically palliative care) were also consistent with the medical model. As a result, the greatest improvements in end-of-life care have occurred in the areas of pain and symptom management (Erskek & Wilson, 2003). More recent definitions of palliative care have expanded to include multiple domains, to use patient satisfaction as one of the criteria for evaluation, and to include family members as components of the unit of care (World Health Organization, 1990).

A number of organizations have taken positions consistent with this conceptualization. The National Hospice and Palliative Care Organization (2004) asserts that emotional and spiritual support be expressly tailored to the patient's needs and wishes and provided to the patient's loved ones as well. The American Geriatrics Society (1997)
statement of principles indicates care at the end of life should address physical and emotional symptoms; function and autonomy; advance care planning; aggressive care near death; patient and family satisfaction; global quality of life; family burden; survival time; provider continuity and skill; and bereavement (American Geriatrics Organization, 2004). The United States Department of Veteran’s Affairs and the Alzheimer’s Association state that for persons with dementia, high quality end-of-life care should treat the whole person, reflect individual preferences, and be culturally sensitive (Volier, Hurley & Blasi, 2001).

Donabedian Health Care Model

Quality of care can be further understood within the Donabedian (1966) health care quality model of structure/process/outcome. Structure refers to the attributes of the care setting, process denotes what is done in providing care, and outcome is the effect on the patient. In the case of long-term care, structure includes staffing adequacy and training; process is the manner of care that recognizes treatment preferences; and outcome would be a “good” (or bad) death. This model has been successfully applied by researchers studying end-of-life care in long-term care settings (Lynn, 1997; Stewart, Teno, Patrick, & Lynn, 1999; Zimmerman, et al., 2005). However, in end-of-life care, the application requires modification of the healthcare quality definition that typically focuses on recovery, restoration of function, and of survival (IOM, 1997). These goals are not consistent with the notion of a good death. Therefore, this model is modified to denote specific outcomes associated with the dying process, such as freedom from pain.

Need for More Research

There is a paucity of information written about the end-of-life experience or what is important at the end of life in long-term care settings. Much of the existing research in end-
of-life care has focused on community-dwelling cancer patients whose death trajectory is predictable and who may remain cognitively intact until actively dying (Webster & Kristjanson, 2002). In contrast, the long-term care population is older and more likely to suffer from dementia and experience chronic illness for long periods prior to death. Thus, what constitutes a “good” death for those who die in long-term care settings may be somewhat unique to the characteristics of this population and the setting in which they die. Given the increasing numbers of individuals who live and die in long-term care, understanding the components of a good death is a timely and highly practical matter.

As death into old age becomes a reality, it has gained the attention of the scientific community. In 2001, the United States National Institutes of Health convened an Integrative Workshop on End of Life Research. Proceedings noted insufficient research on the experience of dying, cautioning that most existing studies have been conducted in acute care settings and over-represent persons with cancer. Also, recommendations were made to examine issues beyond medical care and symptom management, such as the influence of religion and support networks; to attend to the depersonalization of dying (Kayser-Jones, 2002; Sulmasy, 2002); and to obtain population-level information on the quality of end-of-life care from patients and their families (Clark, 2003; Singer & Wolfson, 2003). More recently, the Agency for Healthcare and Research Quality (AHRQ) identified the need for research on methodological challenges (e.g., use of surrogate respondents, cognitive thresholds), measurement development in important settings (specifically NHs), and characterization of the end of life in populations other than cancer patients (Lorenz, et al., 2004). These findings support the conclusion that demographic and care giving realities will
continue to dictate that long-term care will remain a major provider of end-of-life care (Teno, 2002) and that there is good cause to undertake study specific to this area.

In order to address some of these issues, this research examines the post-death responses of family members of long-term care decedents and considers the components they find important at the end of life. Data are organized in accordance with the structure/process/outcome paradigm as appropriate. The research for this paper is not an attempt to evaluate quality of care and consequent outcomes. Rather, its purpose is to establish components of care relevant in the long-term care setting based on the family voices and as indicated by the substance and frequency of their responses.

Study Methods

The NIH-funded study, End-of-Life in Assisted Living and Nursing Homes, collected data on 792 resident deaths in a stratified, random sample of 199 RC/AL facilities and 31 NHs across four states, to describe, compare and evaluate the structure and process of EOL care and how they relate to outcomes (e.g., pain and symptoms). The study is significant in representing both NHs and RC/AL facilities.

Participants and Recruitment

Between July 2002 and January 2005, facilities were contacted on a monthly basis and asked about any deaths that occurred during the previous month. Deaths were considered eligible if decedents died at the facility or within three days of discharge, and if the decedent resided in the facility for at least 15 days in the last month of life.

Subjects were the staff and family caregiver of decedents who, per facility report, was most involved in care during the last month of life. The analyses for this paper use only the family data. Letters were sent to family members approximately eight weeks after the
decedent death; approximately two weeks later, the family member was contacted by telephone. Consent was obtained by telephone prior to conducting the interviews and all procedures were approved by the Institutional Review Board of the University of North Carolina. Some data was collected on 792 decedents and 451 family caregivers completed post-death interviews. Missing family data were due to refusal (21% of cases) and being out of designated six-month time frame (23%).

Data Collection

Data collection consisted of retrospective (within six months of death), structured telephone interviews regarding the care provided to the resident in the month preceding death, resident experiences, the trajectory of the dying process, and family and staff involvement in and satisfaction with care.

At the conclusion of each interview, respondents were asked two open-ended questions concerning that last month of life: 1) “What was done, by either or both the family and staff, that most helped your family member?” and 2) “In your view, what could have been done to make that last month of life better?”

Analysis

Of the 451 family interviews, 437 family members answered both questions (what most helped resident and what could have been done better). Multiple responses were allowed and 1932 responses were coded. Data were analyzed using ATLAS/ti, Version 5.0 (Scientific Software, Berlin, 2004). No a priori coding frame was established before beginning the analysis; instead, codes emerged from the data. Some codes (e.g., “being there”) were developed using the actual words of the respondents (also known as “in vivo” coding). Then, an iterative coding process (the constant comparative method) was used,
combining related codes and developing new ones as they emerged. In this way, 80 codes were identified. For example, “being there” was coded only if the family member indicated he/she was at the facility to “be there” or to visit. If family members indicated they monitored or provided care, those items were coded uniquely (“family care monitoring” and “family care provision,” respectively). Likewise, the code “nothing” was reserved for responses in which the respondent indicated nothing more could have been done. If the response was “don’t know,” that response was coded differently. To maintain accuracy, the actor (care provider or recipient) was reflected in the coding scheme when possible. For example, staff-family communication was differentiated from staff-staff communication.

Codes used 20 or more times are described herein as they represent 67% of all responses. Atlas/ti automatically calculates frequencies and links text to codes.

Results

The 437 family respondents of the 437 decedents who had lived in 26 NHs and 105 RC/AL facilities were largely white (91%) and female (73%) with an average age of 61 years old. Two-thirds were adult children of decedents, 9% were spouses, and 19% were other family (e.g., siblings, nieces or nephews). Over half (58%) worked full-time, and almost half (49%) had a college education or higher.

Data were organized within the structure/process/outcome paradigm (see Table 3.1). Family respondents talked about the quality of care based on the structure of care (e.g., staffing adequacy, staff training, staff consistency, facility environment, and facility size) and the process of care (e.g., staff attitudes, physical symptom management) as related to desirable care outcomes such as comfort and cleanliness. The numbers beside each code indicate the number of times this code was used within the entire coding frame.
Structure of Care. When asked what could have been done to improve the last month of life, the most frequent structural response was: “more staff” or “more educated staff.” Some responses were more specific: “If they could have had more staff to deal with cleanliness and toileting issues” or “More staff and more educated staff to deal with food and eating.” Family members indicated a desire for consistent staff assignment and cited frequent staff turnover as a problem affecting resident well-being: “Staff turnover upset her - she wanted familiar staff.” Families also requested more education for staff, especially around end-of-life issues. For example: “more education for staff about geriatric issues, dementia, and end of life issues.”

Other structural components related to the facility itself. Some families valued small facilities, stating: “Being in a small facility - people got individual attention” and “it was a small facility and the regular staff there knew her.” Some statements described small facilities as homelike and intimate. Respondents also described residents and staff in small facilities (including administrators) as family.

Process of Care. Responses from this study indicated that the most important component of care was a variation of being there (379 endorsements). “Being there” provides a simple definition of a complex phenomenon; it appears to represent social support, usually from family, although the term “social support” itself is used infrequently. Instead, family members talk about: “be there with her;” “being there for her,” and ”just my visiting.” Bringing children and grandchildren to visit was thought to promote a higher quality of life for residents. For example: “…bringing the great grandbaby for visits. She was so depressed, regardless about what she did, she wouldn't smile. But the baby helped.” Family members indicated a desire to have been there more; in other words, while the best thing done was
“being there,” it would have been better if family, friends and staff had been there more often or other family members had also been there.

While many responses documented family involvement, they also indicated staff relationships as an essential component of care, for example, “Also staff visits, they enjoyed spending time with her too.” Other residents also contributed to care: “She loved the staff and her roommate.” One example illustrates the integration of quality of care and quality of life: “The other staff members were very helpful because they would sit and talk with him a lot. They kept his spirits up, made him laugh and they kidded around with him.” And one respondent summarizes the intimate and multifaceted staff/resident relationship as: “Being friendly…Being family…Being there.”

Direct care also was mentioned frequently by family respondents. This included positive responses such as: “Staff checked her frequently” and “attention she got—details taken care of.” There were also negative descriptions: “… if the staff had done little things such as mouth care and human touch.” Families frequently described staff attitudes as primary in importance. The frequency of this response (126 endorsements) appears to place a premium on attitude over education (42 endorsements) as illustrated by: “Staff were very kind, if not smart about certain things…Staff were sincere, if not very informed.” This empathetic attitude is operationalized in the way staff treated the resident: “Being good and kind to her;” “I think the way they treated her, the respect and dignity they gave her;” or “the love staff showed him.” Some family members indicated the staff administered this care under less than ideal circumstances, for example: “Everyone [at the facility] continuing to be attentive and compassionate even though she herself [resident] was extraordinarily difficult and nasty.” However, some family members indicated staff attitudes could have been
improved: “I think the staff could have been more pleasant.”

Other components of the process of end-of-life care that most helped or could have improved the end of life were mentioned fewer than 30 times. Family members often indicated that they monitored and/or provided care themselves during the last month of life. Physical symptom management, specifically pain management, was part of both negative and positive descriptions of care provision, and was mentioned 24 times. For example: “if staff had attended to her pain; the doctor was negligent.” Third party care providers (e.g., private caregivers and Hospice) were frequently described as helpful (e.g. “Hospice was wonderful”) or in the context that their presence would have been helpful: “If he could have had a private nurse or sitter for the last month” or “putting her in Hospice earlier.” Similarly, individualized and one-on-one care was valued as indicated by: “attention from staff that was individualized” and “staff got to know him and his individual needs.” However, 146 of 437 family respondents indicated that nothing more could have been done.

*Outcomes of Care:* The most frequent resident care outcome discussed by families was being “comfortable.” This term may encompass a number of issues, not specified in the data. Family members mentioned comfort in connection with care provision and support: “Staff just being there and keeping her comfortable.” Family also linked staff attitude with comfort: “The staff was very sympathetic and caring; they did all they could to keep her comfortable” or in the negative case “Staff….could have cared more about her made sure she was comfortable.”

The outcome of interest here is that of a good death; however, families did not talk in those terms. However, the circumstances of death still were discussed. Families indicated they were concerned about the place of death; they wished the resident could have been in
the family home at the time of death. This is poignantly stated as: “I wish I could have brought him home” and “He would have been happier if we had brought him home, but that was impossible.”

Discussion

Examining the family voice, in conjunction with organizational and expert opinion, leads to three areas worth discussing. First, the substance and frequency of responses from family indicate that intangibles (being there, staff attitudes, construct of home) are important in considering the quality of care at the end of life for residents of long-term care. In fact, family members mention these intangibles more often than physical symptom management at the end of life. Rather than assuming that families do not care about symptom management, however, it seems likely that they consider companionship and positive attitudes as within the purview of long-term care. Interestingly, this sentiment is congruent with that of Donabedian at the end of his own life. When Donabedian was faced with his own terminal illness, he realized that quality in the hospital setting was limited to technical competence, and that only superficial attention was paid to interpersonal competence. While maintaining that quality of care is difficult, he said:

“Systems awareness and system design are not enough...Ultimately, the secret of quality is love. You have to love your patient, you have to love your profession, you have to love your God. If you have love, you can then work backward to monitor and improve the system.” (Mullan, 2001, p. 140).

It is important to note the frequency with which family members talked about attitudes and empathy using words like kindness, love, family, and relationships as important domains of quality of care, quality of life, and quality of death for residents of long-term care. Most
family members indicated a preference for tender loving care, provided by empathic caring staff, rather than more elegant facility environments or technically advanced medical treatments.

This preference is consistent with conclusions that long-term care staff also value the relationship component of end-of-life care (Zimmerman, Sloane, Hanson, Mitchell & Shy, 2003). The literature supports consideration of the reported outcomes, most notably dignity and “not dying alone” (Johnson, 1998). While mentioned infrequently (four endorsements) and not shown on Table 1, dignity may be embedded in other concepts and is congruent with the family preferences described herein. In one instance, dignity was seen as an outcome of facility size as illustrated by: “His dignity was maintained because it was a small, private facility.” While not dying alone received five endorsements, family members indicated a desire to have been at the bedside at the time of death. Those who were not present at time of death expressed disappointment or anger such as: “I was very angry about this…staff didn't call family when she was passing. We would have been there with her if they had called.” Families were grateful for facility support in their being present at this critical time stating: “The facility was amazing- they let us stay over night, gave us food and our own living room.”

Second, Donabedian’s (1966) seminal article describes a related cross-cutting issue: standards for quality measurement. He describes standards as empirical (i.e., derived from actual practice and comparing medical care between settings or statistically) and normative (based on established standards within the medical care system). In this context, the quality of care can be compared across settings (empirical) or measured against the best possible care provision (normative). Reflecting the normative standard, one family member stated:
“She didn’t get the best treatment overall” or “given the best possible care.” However, there are also indications of the empirical definition: “They did the best they could under the circumstances.” Of the 437 family respondents, 146 said that nothing more could have been done. The exact reasons for the frequency of this response are not known; however, these data suggest that families are aware that better care exists, but are acknowledging limitations of care in the long-term care setting.

Three groups of stakeholders are involved in defining and examining the quality of end-of-life care: 1) the resident; 2) health care providers (doctors, physicians’ assistants, licensed facility staff and paraprofessional facility staff); and 3) family and close friends. Each of these groups provides information useful in defining and evaluating the quality of care. However, their legitimacy differs dependent upon the construct under examination. For example, when defining or evaluating quality of care at the end of life, some researchers believe the staff has a predominant role as they set the standard of care (Higginson & Romer, 2000) as staff assess, treat and monitor patient needs and care provision. However, as evidenced throughout this paper, families apparently have much to say about the quality of care, and many of their suggestions seem able to be easily incorporated into care provision.

The most important implication for social workers may be the lack of reference to this profession. Of a total of 1932 responses, there were only 13 (.7%) references to social workers by profession or indications of the need for a patient advocate: “I didn’t know how to get help and the social worker didn’t attend to it.” While social workers are not part of the regulatory requirements for RC/AL facilities, their presence is mandated in NHs with over 120 beds (Department of Health and Human Services, 1989). They are charged with assuring residents’ rights and maintaining residents’ dignity within these settings. Social workers
advocate for residents and families to receive resident-specific medical treatments, based on resident preferences. They are uniquely trained in case management and how to identify and provide resources for residents and families at the end of life. Social workers also facilitate communication between care providers, especially between physicians and residents and their families. For cognitively impaired residents, social workers are instrumental in assuring that end-of-life wishes are honored. And, social workers are a source of strength to families (and staff) in dealing with their own reactions to resident deaths. Thus, these findings suggest that healthcare quality at the end of life in long-term care will be improved if the social worker’s helping role becomes more evident.
Table 3.1: Substance and Frequency of Codes: “What Was Done That Most Helped” and “What Could Have Been Done to Make Better”

<table>
<thead>
<tr>
<th>Structure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Adequacy (67)</td>
<td>“Being There” (379)</td>
<td>“Home” (73)</td>
</tr>
<tr>
<td>Staff Training (42)</td>
<td>Staff Attitude/Empathy (126)</td>
<td>Comfortable (40)</td>
</tr>
<tr>
<td>Staff Consistency (40)</td>
<td>Staff Direct Care (102)</td>
<td>Clean (23)</td>
</tr>
<tr>
<td>Facility Environment (39)</td>
<td>Hospice (98)</td>
<td></td>
</tr>
<tr>
<td>Facility Size (31)</td>
<td>Resident Preferences (49)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family Emotional Support (39)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Staff-Resident relationship (35)</td>
<td></td>
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<tr>
<td></td>
<td>Family Care Monitoring (29)</td>
<td></td>
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<tr>
<td></td>
<td>Family Care Provision (24)</td>
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<tr>
<td></td>
<td>Physical Symptom Management (24)</td>
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<tr>
<td></td>
<td>Private Caregiver (21)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Individualized Care (20)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social Work Support (13)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Numbers in parentheses are number of times the code appears in the overall coding frame. All codes noted 20 or more times are listed. The code “Social Work Support” is also listed, as it is of special interest to the readers of this journal.
CHAPTER 4
MEASURING THE QUALITY OF DYING IN LONG-TERM CARE

Introduction

Each day more than 1000 Americans die in nursing homes (NHs) and an approximate 500 die in residential care/assisted living (RC/AL) facilities (facilities not licensed as NHs that provide room, board, assistance with activities of daily living, and protective oversight) (CDC, 2002; National Center for Assisted Living, 2001). Annual mortality rates range from 14% in RC/AL facilities (Zimmerman, et al., 2005) to 34% in NHs (Kiely & Flacker, 2003). Further, those who enter NHs typically do not leave, with as many as two thirds of NH residents dying there rather than in hospitals or private homes (Hanson, Henderson, & Rogman, 1997). In fact, experts contend that demographic and financial realities will continue to dictate that NHs “are now and will continue to be, the major provider of care for the dying” (Teno, 2005, p. 2). Yet, the dying experience in long-term care (LTC) has remained largely unexamined.

One notable reason for this gap in knowledge is the lack of empirically designed and psychometrically sound instruments to describe this experience in LTC (Tilden, Tolle, Drach, & Hickman, 2002). Only one instrument, the Toolkit After-Death Bereaved Family Member Interview, (Teno, Clarridge, Casey, Edman-Levitan & Fowler, 2001) is purposed for the LTC setting; however the heterogeneity of the validation sample confounds the construct validity for LTC. For example, the original sample (n = 156) does not adequately reflect the LTC population (only 21% of sample [33 cases] list a NH as the site of death). This is a significant
problem, because the setting of care affects many components of the end-of-life experience such as the philosophy of care, relationships with caregivers, caregiver expectations, staff skill and availability, and financing (Mezey, Dubler, Mitty, & Brody, 2000). Further, LTC residents are older than other patient populations or community-dwelling older adults (i.e., 95% are > 65 years of age), more debilitated by chronic disease with less predictable disease trajectories, and have higher levels of cognitive impairment (US Census Bureau, 2005). This last decedent characteristic also suggests that LTC quality measures, more so than those for other settings, should be designed for use with surrogate respondents. However, the Took-Kit measure is designed for use with family members only, not all of whom are available for LTC decedents. Finally, the measure relates only to the last 48 hours of care, and includes an uncharacteristically large population of Hospice recipients (Schockett, Teno, Miller, & Stuart, 2005).

Some other multi-dimensional instruments (e.g., the McGill Quality of Life Questionnaire [Cohen, et al., 1995; Cohen, et al., 1997]; the Hospice Quality of Life Index [McMillan & Mahon, 1994]; the Schedule of the Evaluation of the Individual Quality of Life [O’Boyle & Waldron, 1997]; the Missoula-Vitas Quality of Life Index [Byock & Merriman, 1998]; the Quality of Death and Dying [Patrick, Engelberg, & Curtis, 2001] and the Quality of Life at the End of Life [Steinhauser, et al., 2002]) have been developed to measure quality at the end of life [Steinhauser, Clipp, & Tulsky, 2002]). These instruments have been validated in acute-care settings on patients with somewhat more predictable disease trajectories than those in LTC, and who, unlike the many LTC decedents who are cognitively impaired prior to death, remain cognitively intact until actively dying (O’Boyle & Waldron;
Morris, et al., 1986; Kayser-Jones, 2002). These measures, therefore, cannot be generalized
to the LTC setting without modification.

Measures of quality may focus on quality of care such as satisfaction with and
outcomes of the process of care or on quality of life (i.e., expectations vs. reality) while
living with serious or life-threatening illness (Higginson & Romer, 2000). Data can be
collected before death to examine quality of care and/or quality of life; however, after-death
interviews must be conducted with surrogate respondents to measure quality of dying, which
differs from quality of care and quality of life as it includes the circumstances of death which
cannot be examined prospectively (Patrick, Engelberg, & Curtis, 2001).

This paper presents the development and psychometric testing of the Quality of
Dying in Long-Term Care (QOD-LTC) scale. It presents two versions of this scale, one for
all decedents and one for those who were cognitively intact preceding death. Items for the
QOD-LTC were partially drawn from the Quality of Life at the End of Life (QUAL-E)
measure (Steinhauser, et al., 2002). The QUAL-E was validated in an ambulatory care
population which differs significantly from the LTC population (Tilden, Tolle, Drach &
Hickman, 2002; Steinhauser et al., 2002; Steinhauser, et al., 2000); however, in the absence
of a well-validated LTC measure, the rigorous and systematic development of the QUAL-E
provides the best available information on domains known to be important at the end of life.

Development of the QUAL-E began with twelve focus groups with a diverse group of
respondents who were asked to identify the attributes of a good death. Findings from this
qualitative study were developed into a national survey, which asked respondents to rate the
importance of 44 attributes using a 5-point Likert scale (Steinhauser, et al., 2000;
Steinhauser, et al., 2001). Items considered important by 80% of respondents were retained
for initial development of the QUAL-E which is comprised of five multi-item domains: (a) completion; (b) relationship with healthcare system; (c) preparation; (d) symptom impact; and (e) affective social support (Steinhauser, et al., 2002). In addition, the QUAL-E items were modified to assess the quality of dying in LTC as learned through post-death interviews with staff and family respondents.

Methods

Design

This project, one of the Collaborative Studies of Long-Term Care (CS-LTC), collected data for 792 resident deaths in a stratified, random sample of 199 RC/AL facilities and 31 NHs across four states (FL, MD, NC, NJ). The purpose of the study was to describe experiences at the end of life as well as compare the structure and process of end-of-life care. In this study, RC/AL facilities are those whose residents are primarily older adults (i.e., 65 years of age or older), are not licensed as a NH, and provide residents with room, board, and assistance with activities of daily living (Zimmerman, Sloane, & Eckert, 2001). Each month facilities were contacted and asked about any deaths that occurred during the previous month.

Subjects

Subjects were family and staff caregivers of residents who died in NHs and RC/AL facilities or if discharged prior to death, died no more than three days post-discharge, between July 2002 and January 2005. Because this study aimed to capture those who received end-of-life care in LTC, a resident’s death was eligible only if that person had resided in the facility for at least 15 of 30 days prior to death. Of the 230 facilities in the sample, 148 (117 RC/ALs and 31 NHs) reported on at least one eligible death during the time of their participation (which averaged 13.5 months [SD = 8]). For each eligible death, the
facility liaison identified the primary family and staff caregivers for interview. The primary family caregiver was the family member, legal guardian or friend who was most involved in care during the last month of life. Family members were eligible if they visited and/or spoke with resident or staff at least once during that time. The primary staff caregiver was the facility staff member who knew the resident best and provided at least one of the following services during the last month of life: direct care, supervision of direct care, passing medications, communicating with family members, and/or arranging services. Staff were contacted by telephone and asked to participate in an interview. Letters were sent to family members approximately eight weeks following the resident’s death, after which time the family respondent was contacted by telephone. Consent was obtained prior to conducting interviews and procedures were approved by the Institutional Review Board of the University of North Carolina.

Data were obtained for 792 decedents. Of those, 451 had interviews with family caregivers, and 677 had staff interviews. Because some staff caregivers provided data for multiple decedents, there were 332 different staff respondents for the 677 decedent interviews.

Measures

Each of the 31 QUAL-E items was examined for content validity based on its empirical derivation as well as theoretical relevance. To reflect dying in LTC, the investigators determined that items considered for the QOD-LTC measure should reflect dying overall and also the special circumstances of care in the LTC setting (e.g., include items related to relationships with direct care staff who provide 90% of the care in these settings) as well as recognize the dementia-related impairment of many of the decedents.
(e.g., use the family as the referent for some items). Also, because the study design dictated it, the measure needed to collect data from surrogate respondents post-death. Each QUAL-E item was examined in light of these requirements. The five QUAL-E items dealing with symptoms identified by the respondent were replaced by two similar items measuring effectiveness of treatment for pain and shortness of breath. Therefore 21 items were retained with some modification (See Figure 4.1).

*Item Supplementation.* The QUAL-E had omitted items not considered important to all respondents. As these items could reflect the special nature of the LTC setting, the investigators returned to the original items and reviewed attributes considered important by 70% of the four national survey respondent groups (i.e., patients, bereaved family members, physicians, and other care providers), as well as items considered important by more than 80% of patients regardless of their importance to other respondent groups in order to capture the patient voice. This process resulted in the addition of 13 items to the retained 21. One additional item was authored by the research team for consideration in the QOD-LTC: “[RESIDENT] was able to maintain [HIS/HER] sense of humor.”

*Instrument Refinement.* The resulting 36 items were those tested in this study. Investigators determined that surrogate respondents (both family and staff) for cognitively intact decedents could be asked all 36 items. However, only 15 items were determined suitable for administration to surrogates for cognitively impaired decedents as those that could be known based on observation or prior knowledge of the resident or could be answered from another perspective. For example, respondents for intact residents were asked if the decedent was at peace with God; this item was not included in the version for respondents of impaired decedents. Therefore, two versions of the QOD-LTC were tested.
with 36 and 15 items, for intact and impaired decedents. For items other than those related to physical symptoms, responses to the query “How true is it that …” are rated on a five-point Likert-type response scale (not at all, a little bit, a moderate amount, quite a bit, completely). Further, a “don’t know” option is available. For the physical symptom items respondents rated the absence or presence of pain and shortness of breath and the effectiveness of care if the symptom was present.

*Cognitive Status.* Resident cognitive status was determined from a series of questions related to diagnosis of Alzheimer’s disease or another dementia (at three months and one month prior to death) and presence of confusion or memory deficits, as well as the patient’s ability to speak or write in a meaningful way in the last month of life. Staff respondent information determined cognitive status when a staff interview was available; however, family respondents also were asked about cognition and these data were used for decedents who lacked a staff interview.

*Analysis*

Interviews were evaluated for missing data. Of the 451 family interviews, 12 were excluded from analysis due to missing data regarding decedent competence (n = 8) and having had < 75% of items completed (n = 4). Of the 677 staff interviews, 29 were excluded from these analyses due to missing data regarding decedent competence (n = 5) and having had < 75% of items completed (n = 24). Therefore, data from 439 family interviews and 648 staff interviews were available for analysis. Missing data in these remaining cases were determined to be randomly distributed (per visual examination of scatter plots) and replaced with imputed means. The imputed value was determined by calculating the mean of all completed items for each respondent.
Data for the cognitively intact decedent subgroup derived from 95 family interviews and 149 staff interviews (111 unique staff respondents). To avoid sample bias, only one interview per staff respondent (i.e., the first interview provided) was included in the analyses for each instrument. Therefore the sample consisted of 206 interviews (95 from family respondents and 111 from staff respondents), providing adequate power for exploratory factor analysis (DeVellis, 2003).

Data for the cognitively impaired decedent subgroup derived from 344 family interviews and 499 staff interviews (252 unique staff respondents). Again, the first interview from each staff respondent was included, resulting in a total 596 interviews (344 from family and 252 from staff) for analysis. This sample size provides excellent power for exploratory factor analysis of 13 items (DeVellis, 2003).

Data were entered into SPSS 13.0 (SPSS, Inc, Chicago, Illinois) for analyses. Five items were reverse coded to allow for an overall positive score. All items were evaluated for successful completion, and items were eliminated if they had ≥ 15% cumulative don’t know and/or missing responses. This resulted in the elimination of one item (“[RESIDENT’s] physician felt comfortable talking about death and dying”) from analyses of both instruments; two items (“Beyond his/her illness, resident’s physician knew [HIM/HER] as a whole person” and “[RESIDENT] was able to complete unfinished business”) from analyses for intact decedents; and one item (“[RESIDENT] had a physician whom [HE/SHE] trusted.”) from analyses for impaired decedents. Therefore, 33 items were entered into factor analysis for intact decedents and 13 items for all decedents.

Further, secondary analyses were conducted to confirm/disconfirm factor patterns of all respondents (family and staff) for the 13 items common to all decedents (combined intact
and impaired samples; n = 802). Also, samples of intact and impaired decedents were subsetted by respondent type and secondary analyses conducted to confirm/disconfirm factor patterns found in the primary analysis. After conducting the initial factor analyses, a factor score (mean of items in each factor) was computed and a second-level factor analysis of these factor scores was conducted to test for unidimensionality (i.e., a single underlying construct) of the scale (DeVellis, 2003).

All exploratory factor analyses were conducted with communalities set to one and Promax rotation. Factor extraction was based on multiple criteria: eigenvalues > 1; scree plots; factor interpretability; and an a priori hypothesis of unidimensionality. Iterative analyses were conducted and individual items evaluated for ambiguous factor loadings and factor interpretability. The criterion for the final model was simple structure. Cronbach’s alpha was used to measure internal reliability of the scale and subscales.

Results

Sample

Study decedents (n = 792) were predominantly female (70%) and white (89%) with a mean age of 85.3 years old (SD = 9.4). Less than one quarter (23%) were deemed cognitively intact during the last month of life. Family respondents (n = 451) also were predominantly female (73%) and white (93%) with a mean age of 60.5 years old (SD = 11.5). The majority of family respondents were adult children of the decedent (67%) or other family (e.g., spouse, niece, nephew, sibling; 19%). Almost two-thirds (63%) of staff respondents (n = 332) were white, and over one quarter (29%) were black. The mean age was 43.6 years (SD = 11.5). Over half (53%) of the staff respondents were licensed nurses.

Item Response Characteristics
The 36-candidate items demonstrated variability across all response categories (i.e., from “not at all” to “completely”). However data were positively skewed. One item for cognitively intact decedents, “[RESIDENT] worried about being a burden to society” had the highest endorsement and showed the least variability (mean = 4.84, SD = 0.64). The item with the lowest endorsement was: “[RESIDENT] was able to maintain [HIS/HER] sense of humor” (mean = 2.92, SD = 1.66). Table 4.1 presents the means and distributions of items for both cognitively intact and all decedents.

**Domains of the QOD-LTC for Cognitively Intact Residents (QOD-LTC-C)**

Following the elimination of three items that could not be answered by ≥ 85% of respondents, the remaining 33 items for cognitively intact residents were entered into factor analysis during which four items (comfort with nurse or aide; could say good-bye to important people; cleanliness; information about illness) loaded ambiguously or did not factor and were not retained in the final model.

Exploratory factor analysis of the remaining 29 items resulted in seven distinct interpretable factors (factor correlations ranging from .006 to .409). However, second-level analyses of the factor scores indicated only five factors demonstrated unidimensionality (i.e., reflected a single latent variable) and were retained in the final QOD-LTC-C (see Table 4.2 and the Appendix for a copy of the actual measure).

The first factor (6 items, \( \alpha = .847 \); 25% of item variance) reflected completion. These items related to helping others; making a positive difference in the lives of others; sharing important things with family; having meaning in life; saying important things to those close; and retaining a sense of humor.
The second factor (5 items, $\alpha = .757$; 11% of item variance) reflected closure on the part of the decedent. The strongest item indicated the decedent felt prepared to die. Other items reflected that: thoughts of dying frightened the resident, the resident regretted the way he/she lived life, the resident appeared at peace; and the resident was at peace with God.

Factor 3 (4 items, $\alpha = .735$, 8% of item variance) described the decedent’s relationship with the healthcare system. These items included having a sense of control, participating in treatment decisions, knowing who to ask questions, and knowing what to expect about illness.

Factor 4 (5 items; $\alpha = .667$; 6% of item variance) indicated components of affective social support, specifically: having someone to share deep thoughts; having a trusted doctor; receiving compassionate physical touch; spending enough time with family; and maintaining dignity. The fifth factor, preparatory tasks, contained 3 items ($\alpha = .540$; 6% of item variance): which described having: appointed a decision maker; planned funeral arrangements; and had treatment preferences in writing. The resultant five factors (23 items) comprised a scale with an overall alpha of .849 (very good) (DeVellis, 2003). Separate analyses of family and staff samples produced similar results.

Domains of the QOD-LTC

Following elimination of the two items that could not be successfully answered by $\geq 85\%$ of respondents, exploratory factor analysis of the remaining 13 items considered for the QOD-LTC resulted in four distinct factors with factor correlations ranging from .003 to .242. The second-level analysis of the factor scores indicated three factors demonstrated unidimensionality and should be retained for the final measure (see Appendix for the complete measure). Table 4.3 shows the results for the impaired decedents and all decedents,
the results of which are essentially the same. The first factor, dignity, consisted of five items ($\alpha = .597$; 24% of item variance) which indicated that the resident was kept clean, received compassionate physical touch, dignity was maintained, the doctor knew the resident as whole person, and there was a nurse or aide with whom the resident was comfortable. Factor 2, closure, (3 items; $\alpha = .502$; 13% of item variance), indicated that the residents retained a sense of humor, indicated he/she was prepared to die, and appeared at peace. The third factor, preparatory tasks (3 items; $\alpha = .487$; 12% of item variance) was equivalent to the QOD-LTC-C factor indicated that resident had treatment preferences in writing, had appointed a decision-maker, and had planned funeral arrangements. Cronbach’s alpha for the resultant scale reached an acceptable (DeVellis, 2003) level of .639 for impaired decedents and .655 for all decedents and explained 48% and 49% of the item variance respectively. Secondary analyses of separate family and staff samples produced similar results.

Discussion

The QOD-LTC is a promising measure of the quality of dying in NHs and RC/AL communities and is the first instrument developed solely for and tested in these settings. Both the version for cognitively intact decedents and the one for all decedents constitute a multi-dimensional reflection of the underlying construct, the quality of dying. Factor scores (means of item scores within each factor) may be averaged for an overall quality of dying score, with a higher score indicating a more positive experience. Also, individual factor scores may be used separately. However, there are some limitations of these measures that call for additional refinement and testing.

The QOD-LTC provides a multi-dimensional assessment of the quality of dying for all LTC residents including those who are cognitively impaired. As rates of cognitive
impairment are high in this population (77% in this study and ranging from 18 to 67% in RC/AL facilities [Phillips, Holan, Sherman, Specter & Hawes., 2005; Morgan, Gruber-Baldini, & Magaziner, 2001; Burdick, et al., 2005] and 25 to 95% in NHs in earlier studies [Magaziner, et al., 2000; Hall, Schroeder, & Weaver, 2000), an instrument of this type is needed. Notably, only two of these items were included in the original QUAL-E (i.e., “Physician knew [RESIDENT] as a whole person” and “[RESIDENT] appeared to be at peace”) suggesting that the QOD-LTC captures constructs specific to the LTC setting and population.

The strongest factor, dignity, indicates decedent dignity is an important component of the underlying construct. It further suggests that, in the face of other losses (e.g., health, cognitive awareness, relationships, life), dignity is fundamentally important to the quality of dying in LTC. Indeed, other studies demonstrate that dignity becomes more salient as one approaches death (Chochinov, Hack, McClement, Kritjansons & Harlos., 2002) and that maintaining dignity may be as important as controlling pain (Johnson, 1998). In this study, it is notable that the QOD-LTC items related to this factor included contributions from facility staff (compassionate physical touch, cleanliness care, a nurse or aide with whom comfortable) as well as a doctor who knew the resident “as a whole person”. This combination of items suggests that a death with dignity involves an interactive process between the dying individual and his or her caregivers (Back, Wallace, Starks, Starks & Pearlman., 1996) and that they are, at least in part, responsible for maintaining dignity for the cognitively impaired decedent. As dignity is equated with human worth (Johnson), maintaining the resident’s dignity by keeping him/her clean, acknowledging his/her personhood, and providing physical touch affirms the worth of the dying person.
Further, the QOD-LTC-C provides a more comprehensive picture of the dying experience by including additional items appropriate for surrogate respondents of decedents who were cognitively intact during the last month of life. For example, the realization of closure and the presence of affective social support are important to dying residents (Steinhauser, Christakis, Clipp, et al., 2000; Steinhauser, Christakis, Clipp, et al., 2001). Surrogate respondents for intact decedents can provide information regarding these aspects of the dying experience based on decedent statements in addition to their own observations.

Although the use of surrogate respondents in healthcare research is subject to criticism, surrogate respondents are necessary to measure quality for patients who cannot speak for themselves. Recent findings indicate that surrogate respondents provide valid data on a number of end-of-life issues (McPherson & Addington-Hall, 2003). For persons with dementia, or those who are actively dying or have died, surrogate respondents provide information for which there is no other source. In end-of-life research, the use of surrogates enables researchers to conduct studies post-death. Such retrospective studies are necessary in those cases when uncertain prognoses and disease trajectories often prohibit inclusion prior to death (Fowler, Coppola, & Teno, 1999; Teno & Coppola, 1999). This is especially important for the LTC population, characterized by long periods of physical and functional decline prior to death (Covinsky, Eng, Lui, Sands & Yaffe, 2003).

Historically, surrogate respondents have provided insight into end-of-life care provision, identified areas for quality improvement, and detailed information concerning the decedent’s pain and symptom management, involvement in decision-making, and satisfaction with care (Teno, Casey, Welch, & Edgman-Levitan, 2001). Further, surrogate respondents can describe circumstances that occur at the time of death that cannot be captured
prospectively (Patrick, Engelberg, & Curtis, 2001). In this study, surrogate respondents had been closely involved with the decedents during the dying process (per facility report). Finally, during administration study interviewers noted “don’t know” responses when appropriate and items that were not successfully answered did not make it into the final measure.

Unfortunately, there were no items related to physical symptoms retained for either version of the measure as this factor violated the a priori assumption of unidimensionality. The literature supports the inclusion of physical symptoms as a component of the quality of dying (Steinhauser, et al., 2000; Phillips, Holan, Sherman, Specter & Hawes, 2005; Teno, Casey, Welch, & Edgman-Levitqan, 2001); therefore, symptom item performance in these analyses suggests the need for further study.

There are some limitations inherent in the analyses as conducted and described. In the initial analyses of the QOD-LTC-C, family and staff respondent groups were combined to obtain adequate power. While this is not ideal, secondary analyses confirmed the overall stability of the factor pattern in smaller, homogeneous samples. On the other hand, the sample sizes of the QOD-LTC were robust and represent the strength of the validation process.

Also, the positive skew of some items limits the use for research purposes. This is a challenge for many rating measures, especially those related to satisfaction (Hinkle, Wiersma, & Jurs, 1998). Further, there may be a concern that staff respondents both provided care and evaluated the quality of care. However, there is no reason to assume that this would influence factor structure. Also, the QOD-LTC provides for surrogate responses by both
family and staff. As such, the QOD-LTC can be used to compare family and staff responses and calculate differences between respondent groups.

Conclusion

When compared with existing instruments, the QOD-LTC represents a unique measure with good psychometric properties that is directed specifically for and tested in the LTC setting. As such, use of this measure can contribute to the understanding and perhaps improving the quality of dying for this vulnerable and growing population.
<table>
<thead>
<tr>
<th>Item</th>
<th>Distributions</th>
<th>Means (SD)(^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
</tr>
<tr>
<td>1. [RESIDENT] had as much information as [HE/SHE] wanted about [HIS/HER] illness.</td>
<td>6 (3)</td>
<td>7 (3)</td>
</tr>
<tr>
<td>2. Although [HE/SHE] could not control certain aspects of [HIS/HER] illness, [RESIDENT] had sense of control about [HIS/HER] treatment decisions.</td>
<td>8 (4)</td>
<td>13 (6)</td>
</tr>
<tr>
<td>3. [RESIDENT] participated as much as [HE/SHE] wanted in the decisions about [HIS/HER] care.</td>
<td>6 (3)</td>
<td>3 (1)</td>
</tr>
<tr>
<td>4. In general, [RESIDENT] knew what to expect about the course of [HIS/HER] illness.</td>
<td>22 (10)</td>
<td>12 (6)</td>
</tr>
<tr>
<td>5. [RESIDENT’s] physician knew [HIM/HER] as a whole person.</td>
<td>116 (19)</td>
<td>55 (9)</td>
</tr>
<tr>
<td>6. As [HIS/HER] illness progressed, [HE/SHE] knew where to go for answers to [HIS/HER] questions.</td>
<td>13 (6)</td>
<td>6 (3)</td>
</tr>
<tr>
<td>7. There was a nurse or aide with whom [RESIDENT] felt comfortable.(^b)</td>
<td>36 (4)</td>
<td>17 (2)</td>
</tr>
<tr>
<td>Item</td>
<td>Not at all</td>
<td>A little bit</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
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<td>--------------</td>
</tr>
<tr>
<td>8. [RESIDENT] had a physician whom [HE/SHE] trusted.</td>
<td>13 (6)</td>
<td>9 (4)</td>
</tr>
<tr>
<td>9. [HE/SHE] spent as much time as [HE/SHE] wanted with [HIS/HER] family.</td>
<td>25 (12)</td>
<td>8 (4)</td>
</tr>
<tr>
<td>10. There was someone in [HIS/HER] life with whom [HE/SHE] could share [HIS/HER] deepest thoughts.</td>
<td>18 (9)</td>
<td>16 (8)</td>
</tr>
<tr>
<td>11. [RESIDENT] received compassionate physical touch daily.</td>
<td>8 (1)</td>
<td>10 (1)</td>
</tr>
<tr>
<td>12. [HE/SHE] worried that [HIS/HER] family was not prepared to cope with the future.</td>
<td>23 (11)</td>
<td>6 (3)</td>
</tr>
<tr>
<td>13. [RESIDENT] had regrets about the way [HE/SHE] lived [HIS/HER] life.</td>
<td>5 (2)</td>
<td>4 (2)</td>
</tr>
<tr>
<td>14. At times, [RESIDENT] worried that [HE/SHE] would be a burden to [HIS/HER] family.</td>
<td>27 (13)</td>
<td>18 (9)</td>
</tr>
<tr>
<td>Item</td>
<td>Distributions</td>
<td>Means (SD)</td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
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</tr>
<tr>
<td></td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
</tr>
<tr>
<td>15. [RESIDENT] worried that [HE/SHE] would be a burden to society.</td>
<td>2 (1)</td>
<td>5 (2)</td>
</tr>
<tr>
<td>16. Thoughts of dying frightened [HIM/HER].</td>
<td>12 (6)</td>
<td>13 (6)</td>
</tr>
<tr>
<td>17. [RESIDENT] worried about the financial strain caused by [HIS/HER] illness.</td>
<td>11 (5)</td>
<td>14 (7)</td>
</tr>
<tr>
<td>18. [HE/SHE] was able to say important things to those close to [HIM/HER].</td>
<td>8 (4)</td>
<td>5 (2)</td>
</tr>
<tr>
<td>19. [HE/SHE] was able to make a positive difference in the lives of others.</td>
<td>12 (6)</td>
<td>9 (4)</td>
</tr>
<tr>
<td>20. [HE/SHE] was able to help others through time together, gifts, or wisdom.</td>
<td>24 (11)</td>
<td>9 (4)</td>
</tr>
<tr>
<td>21. [HE/SHE] was able to share important things with [HIS/HER] family.</td>
<td>20 (9)</td>
<td>8 (4)</td>
</tr>
<tr>
<td>22. Despite [HIS/HER] illness, [HE/SHE] had a sense of meaning in [HIS/HER] life.</td>
<td>17 (8)</td>
<td>6 (3)</td>
</tr>
<tr>
<td>23. [RESIDENT] appeared to be at peace.</td>
<td>73 (9)</td>
<td>40 (5)</td>
</tr>
<tr>
<td>Item</td>
<td>N (%)</td>
<td>Means (SD)</td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
<td>--------------</td>
<td>-----------------</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
</tr>
<tr>
<td>24. [RESIDENT] had a chance to say goodbye to important people.</td>
<td>51 (24)</td>
<td>11 (5)</td>
</tr>
<tr>
<td>25. [RESIDENT] had treatment preferences in writing. b</td>
<td>98 (12)</td>
<td>6 (1)</td>
</tr>
<tr>
<td>26. [RESIDENT] felt prepared to die. b,d</td>
<td>259 (32)</td>
<td>19 (2)</td>
</tr>
<tr>
<td>27. [RESIDENT] had funeral arrangements planned. b</td>
<td>113 (14)</td>
<td>11 (1)</td>
</tr>
<tr>
<td>28. [RESIDENT] had named a decision maker in the event that [HE/SHE] was no longer able to make decisions. b</td>
<td>40 (5)</td>
<td>1 (&lt;1)</td>
</tr>
<tr>
<td>29. [RESIDENT] was able to retain [HIS/HER] sense of humor. b</td>
<td>207 (25)</td>
<td>93 (11)</td>
</tr>
<tr>
<td>30. [RESIDENT] was able to maintain [HIS/HER] dignity. b,d</td>
<td>32 (4)</td>
<td>17 (2)</td>
</tr>
<tr>
<td>31. [RESIDENT] was at peace with God.</td>
<td>5 (2)</td>
<td>3 (1)</td>
</tr>
<tr>
<td>32. [RESIDENT] was able to resolve unfinished business with family or friends.</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Item</td>
<td>Not at all</td>
<td>A little bit</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------</td>
<td>--------------</td>
</tr>
<tr>
<td>33. [RESIDENT] was free from pain. b</td>
<td>12 (2)</td>
<td>56 (7)</td>
</tr>
<tr>
<td>34. [RESIDENT] was free from shortness of breath. b</td>
<td>31 (4)</td>
<td>57 (7)</td>
</tr>
<tr>
<td>35. [RESIDENT] was kept clean. b</td>
<td>5 (1)</td>
<td>34 (4)</td>
</tr>
<tr>
<td>36. [RESIDENT’s] physician felt comfortable talking about death and dying.</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

a Based on scores from 1 = not at all, to 5 = completely.
b In calculating distribution, n = 802 for items asked of all respondents.
c Item was reverse coded; therefore, higher scores indicate positive outcomes for the individual factor as well as for the summative scale score.
d Worded slightly differently depending on cognitive status of decedent.
* Item with ≥ 15% missing; dropped from analyses.
NA: Not asked; item not considered appropriate for surrogate respondents of cognitively decedents.
<table>
<thead>
<tr>
<th>ITEM</th>
<th>FACTOR 1</th>
<th>FACTOR 2</th>
<th>FACTOR 3</th>
<th>FACTOR 4</th>
<th>FACTOR 5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>COMPLETION</td>
<td>CLOSURE</td>
<td>RELATIONSHIP WITH HEALTHCARE SYSTEM</td>
<td>AFFECTIVE SOCIAL SUPPORT</td>
<td>PREPARATORY TASKS</td>
</tr>
<tr>
<td>[HE/SHE] was able to help others through time together, Gifts or wisdom.</td>
<td>.863</td>
<td>-.019</td>
<td>.026</td>
<td>-.061</td>
<td>-.025</td>
</tr>
<tr>
<td>[HE/SHE] was able to make a positive difference in the lives of others.</td>
<td>.839</td>
<td>.122</td>
<td>-.021</td>
<td>-.130</td>
<td>-.047</td>
</tr>
<tr>
<td>[HE/SHE] was able to share important things With [HIS/HER] family.</td>
<td>.793</td>
<td>-.185</td>
<td>-.010</td>
<td>-.143</td>
<td>-.057</td>
</tr>
<tr>
<td>Despite [HIS/HER] illness, [HE/SHE] had a sense of meaning in [HIS/HER] life.</td>
<td>.737</td>
<td>.062</td>
<td>.005</td>
<td>.011</td>
<td>.020</td>
</tr>
<tr>
<td>[HE/SHE] was able to say important things to those close to [HIM/HER].</td>
<td>.590</td>
<td>-.095</td>
<td>.087</td>
<td>.242</td>
<td>.081</td>
</tr>
<tr>
<td>[RESIDENT] was able to retain HIS/HER sense of humor.</td>
<td>.519</td>
<td>.228</td>
<td>.084</td>
<td>-.019</td>
<td>-.098</td>
</tr>
<tr>
<td>[RESIDENT] felt prepared to die.</td>
<td>-.019</td>
<td>.771</td>
<td>.123</td>
<td>-.201</td>
<td>.160</td>
</tr>
<tr>
<td>Thoughts of dying frightened [HIM/HER].</td>
<td>-.194</td>
<td>.760</td>
<td>.114</td>
<td>.048</td>
<td>-.026</td>
</tr>
<tr>
<td>[RESIDENT] had regrets about the way [HE/SHE] Lived [HIS/HER] life.</td>
<td>.015</td>
<td>.637</td>
<td>-.058</td>
<td>.090</td>
<td>-.049</td>
</tr>
<tr>
<td>[RESIDENT] appeared to be at peace.</td>
<td>.296</td>
<td>.633</td>
<td>-.108</td>
<td>.083</td>
<td>-.082</td>
</tr>
<tr>
<td>[RESIDENT] was at peace with God.</td>
<td>.176</td>
<td>.557</td>
<td>-.136</td>
<td>.081</td>
<td>.014</td>
</tr>
<tr>
<td>Although [HE/SHE] could not control certain aspects of [HIS/HER] illness, [RESIDENT] had sense of control about [HIS/HER] treatment decisions.</td>
<td>.148</td>
<td>-.043</td>
<td>.872</td>
<td>-.125</td>
<td>.035</td>
</tr>
<tr>
<td>ITEM</td>
<td>FACTOR I</td>
<td>FACTOR 2</td>
<td>FACTOR 3</td>
<td>FACTOR 4</td>
<td>FACTOR 5</td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
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<td>------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>[RESIDENT] participated as much as [HE/SHE] wanted in the decisions</td>
<td>0.060</td>
<td>-0.068</td>
<td>0.844</td>
<td>-0.082</td>
<td>-0.133</td>
</tr>
<tr>
<td>[HIS/HER] care.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>As [HIS/HER] illness progressed,</td>
<td>-0.139</td>
<td>-0.013</td>
<td>0.684</td>
<td>0.316</td>
<td>-0.054</td>
</tr>
<tr>
<td>[HE/SHE] knew Where to go for answers to [HIS/HER] questions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In general, [RESIDENT] knew what to expect about the course of</td>
<td>-0.049</td>
<td>0.297</td>
<td>0.560</td>
<td>-0.010</td>
<td>-0.238</td>
</tr>
<tr>
<td>[HIS/HER] illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There was someone in [HIS/HER] life with whom [HE/SHE] could share</td>
<td>0.122</td>
<td>0.027</td>
<td>-0.043</td>
<td>0.717</td>
<td>-0.175</td>
</tr>
<tr>
<td>[HIS/HER] deepest thoughts.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[RESIDENT] had a physician whom [HE/SHE] trusted.</td>
<td>-0.174</td>
<td>0.178</td>
<td>-0.003</td>
<td>0.680</td>
<td>0.088</td>
</tr>
<tr>
<td>[HE/SHE] spent as much time as [HE/SHE] Wanted with [HIS/HER]</td>
<td>0.026</td>
<td>-0.096</td>
<td>-0.064</td>
<td>0.619</td>
<td>0.129</td>
</tr>
<tr>
<td>family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[RESIDENT] received compassionate physical touch daily.</td>
<td>0.112</td>
<td>-0.059</td>
<td>0.052</td>
<td>0.600</td>
<td>-0.004</td>
</tr>
<tr>
<td>[RESIDENT] was able to maintain [HIS/HER] dignity.</td>
<td>0.008</td>
<td>0.205</td>
<td>0.088</td>
<td>0.389</td>
<td>0.251</td>
</tr>
<tr>
<td>[RESIDENT] had named a decision maker in the event that [HE/SHE]</td>
<td>-0.078</td>
<td>-0.117</td>
<td>0.010</td>
<td>0.103</td>
<td>0.731</td>
</tr>
<tr>
<td>was no longer able to make decisions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[RESIDENT] had funeral arrangements planned.</td>
<td>-0.008</td>
<td>0.261</td>
<td>-0.123</td>
<td>-0.036</td>
<td>0.707</td>
</tr>
<tr>
<td>[RESIDENT] had treatment preferences in writing.</td>
<td>0.114</td>
<td>-0.076</td>
<td>0.096</td>
<td>0.004</td>
<td>0.673</td>
</tr>
</tbody>
</table>

Reliability Assessment (Full Scale) Cronbach’s $\alpha = .849$. 
Table 4.3: Factor Loadings of the Final Model (11 Items)
Cognitively Impaired Decedents (Family \[n = 344\] and Staff \[n = 252\] Respondents; \(N = 596\)) and All Decedents (Family \[n = 439\] and Staff \[n = 362\]) Respondents; \(N = 802\)

<table>
<thead>
<tr>
<th>Item</th>
<th>Cognitively Impaired Decedents ((n = 596)^a)</th>
<th>All Decedents ((n = 802)^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Factor 1</td>
<td>Factor 2</td>
</tr>
<tr>
<td></td>
<td>Dignity</td>
<td>Closure</td>
</tr>
<tr>
<td>[RESIDENT] was kept clean.</td>
<td>.755</td>
<td>-.089</td>
</tr>
<tr>
<td>[RESIDENT] received compassionate physical touch daily.</td>
<td>.739</td>
<td>-.300</td>
</tr>
<tr>
<td>[RESIDENT’s] dignity was maintained.</td>
<td>.735</td>
<td>.115</td>
</tr>
<tr>
<td>[RESIDENT’s] physician knew [HIM/HER] as a whole person.</td>
<td>.495</td>
<td>.139</td>
</tr>
<tr>
<td>There was a nurse or aide with whom [RESIDENT] felt comfortable.</td>
<td>.383</td>
<td>.214</td>
</tr>
<tr>
<td>[RESIDENT] was able to retain [HIS/HER] sense of humor.</td>
<td>.004</td>
<td>.748</td>
</tr>
<tr>
<td>[RESIDENT] indicated [HE/SHE] was prepared to die.</td>
<td>-.129</td>
<td>.713</td>
</tr>
<tr>
<td>[HE/SHE] appeared to be at peace.</td>
<td>.355</td>
<td>.503</td>
</tr>
<tr>
<td>[RESIDENT] had treatment preferences in writing.</td>
<td>-.077</td>
<td>-.041</td>
</tr>
<tr>
<td>[RESIDENT] had named a decision maker in the event that [HE/SHE] was no longer able to make decisions.</td>
<td>.046</td>
<td>-.080</td>
</tr>
<tr>
<td>[RESIDENT] had funeral arrangements planned.</td>
<td>.062</td>
<td>.259</td>
</tr>
</tbody>
</table>

\(^a\) Reliability Assessment (Full Scale) Cronbach’s \(\alpha = .639\)

\(^b\) Reliability Assessment (Full Scale) Cronbach’s \(\alpha = .655\)
Figure 4.1: The Selection of Items for Inclusion in the Quality of Dying in Long-Term Care

- 21 QUAL-E Items
- 13 Items from national survey
- 2 item authored for this measure

36 Items Tested

- 36 Items for respondents of cognitively intact decedents
  - 3 Items eliminated (≥ 15% don’t know or missing)

- 33 Items entered into exploratory factor analysis

- 4 Items did not factor

- 7 factors (29 items) entered into secondary factor analysis
  - 2 factors (6 Items) did not demonstrate unidimensionality

QOD-LTC-C
- 5 Factors (23 Items)

- 15 Items for respondents of all decedents
  - 2 items eliminated (≥ 15% don’t know or missing)

- 13 Items entered into exploratory factor analysis

- 4 factors (13 Items) entered into secondary factor analysis

QOD-LTC
- 3 factors (11 Items)

- 4 Items did not factor

- 1 factor (2 Items) did not demonstrate unidimensionality
CHAPTER 5

CONCLUSION

Implications for Policy

Policy in nursing homes has historically focused on increasing regulation toward the goal of improving care. At the same time, inadequate funding and resultant staffing shortages have severely impaired the ability of long-term care staff to meet the needs of increasingly frail elders, especially at the end of life (Miller, Teno & Mor, 2004; Zimmerman, Sloane, Hanson, Mitchell & Shy, 2003). For example, implementation of The Nursing Home Reform Act of 1987 (part of the Omnibus Budget Reconciliation Act of 1987 [OBRA]) (Department of Health and Human Services, 1989) greatly increased regulation yet resulted in only nominal improvements in care provision (Kane, 2006; Wunderlich & Kohler, 2001). Existing studies of end-of-life care in nursing homes confirm that care provision is inadequate especially in areas of pain management and emotional and spiritual support (Teno, et al., 2004; Hanson, Danis & Garrett, 2003; Reynolds, Henderson, Schulman & Hanson, 2002). In contrast, state supervised residential care/assisted living facilities generally have fewer regulations (Zimmerman, Munn & Koenig, 2006). When family satisfaction with end-of-life care in nursing homes and residential care/assisted-living facilities is systematically compared, satisfaction levels are higher within the less regulated and less institutional residential care/assisted living stratum (Sloane, et al., 2003).
Taken together, these data suggest that policy initiatives based solely on increasing regulation without increasing funding for higher staffing levels and instituting quality improvement interventions are unlikely to improve care (Hanson, Reynolds, Henderson & Pickard, 2005; Crickmer, 2005; Miller, Teno & Mor, 2004; Kalliaty & Morris, 2002). Therefore, one standing recommendation for improving care is increased funding through higher levels of Medicaid and Medicare reimbursement. This funding is vital to increase staffing levels, especially for paraprofessional care providers and social workers. The following recommendations are premised upon increased funding levels. Further, these recommendations represent the ideal; they provide a vision for optimal practice guidelines. In that respect, they push the envelope of realism; however, practice wisdom and personal experience suggest that dedicated care providers can attain levels of excellence.

Implications for Practice

This dissertation research was conducted to understand and ultimately improve the quality of care, quality of life, and quality of dying of the approximately 1500 long-term care residents who die each day (Centers for Disease Control, 2002; National Association for Assisted Living, 2001) by providing insights that inform practice. Currently, translational research is acknowledged as a worthy goal in the professional geriatric research and clinical communities (Pillemer, Suitor & Wethington, 2003). Translational research is defined as: “systematic translation of basic behavioral research findings into the development of innovative research interventions that may ultimately improve real-world practices” (National Institute of Mental Health [NIMH], 2000, p. 3). While the dissertation does not represent translational research per se, it does lay the groundwork for recommendations to inform practice.
In the long-term care setting, using research to inform practice involves several disciplines as clinical care is administered by an interdisciplinary team. This team usually consists of physicians, nurses and/or paraprofessional care providers, dietary staff and in some cases social workers, physical therapists, pharmacists, and occupational therapists. In nursing homes, these teams are a formal part of the organizational structure (CMS, 2005); in residential care/assisted living facilities in which residents often retain their personal physicians, these disciplines are represented but interact in a less organized manner. Each team member provides expertise and each has a unique view of end-of-life care provision (Flacker, Won, Kiely & Iloputaife, 2001). Almost one-quarter (22%) of dying long-term care residents also receive care from an interdisciplinary Hospice team (Miller, Teno & Mor, 2004).

The dissertation studies identified three disciplines within the care team as being vital to improving end-of-life care. That is, enhancing the involvement of these three disciplines should consequently enhance care provision. Two, social workers and physicians, were notable by their absence; the third, paraprofessional care providers, were present but underutilized. Therefore, the implications for practice in these three disciplines are discussed below.

**Social Workers**

There are approximately 41,000 professional social workers employed in long-term care settings on the United States (derived from U.S. Department of Health and Human Services, 2006). This statistic includes persons who report social work as their profession; have at least a bachelor’s degree (which may or may not be in social work); and are employed in one of four industries collectively described as long-term care (i.e., a home
health agency, nursing home, residential care/assisted living facility, or community care for the aged) (U.S. Department of Health and Human Services).

Nursing homes with 120 or more beds are mandated to employ a full-time social worker (Department of Health and Human Services, 1989). Social work staff are not mandated in most states for residential care/assisted living facilities (Zimmerman, Munn & Koenig, 2006; Mollica, 2002). However, social work in either of these settings is demanding as there is at best one social worker per facility who has responsibility for identifying medically-related psychosocial needs for each resident and providing and implementing a plan of care to meet those needs (Vourlekis & Simons, 2006). In addition, social workers are responsible for promoting high quality of life for all residents assuring: autonomy, functional competence, privacy, dignity, meaningful activity, individuality, enjoyment, security, relationships, spiritual well-being, and comfort (Kane, 2003). In nursing homes, these responsibilities are coupled with paperwork associated with regulatory requirements (CMS, 2005). Also, social workers often handle both admissions and discharge planning and a variety of other tasks (e.g., finding missing articles, investigating issues of abuse, training staff in residents’ rights) (Vourlekis & Simon).

Most LTC social workers, if they have a social work degree, have bachelor’s rather than master’s level training (Gilberman & Shcervish, 1997). Such minimal standards are hardly sufficient to provide services to residents, family and staff dealing with complex EOL issues. Further, demographic trends suggest more LTC social workers will be required to meet the needs of baby boomers (US Department of Health and Human Services, 2006). Therefore, policy initiatives are needed to support development of master’s level trained social workers competent in practice with older adults and complex end-of-life issues.
Precedents show that increased funding has resulted in higher number of social workers students in these areas (Damon-Rodriguez & Lubben, 1997).

Dissertation Findings

In light of the myriad of daily tasks performed by the LTC social worker and limited training of some LTC social workers, it is understandable, although not acceptable, that social workers were noticeably absent from descriptions of end-of-life care provision in the studies comprising the dissertation as well as the parent study, *End-of-Life in Residential Care/Assisted Living Facilities and Nursing Homes* (Sheryl Zimmerman PI). For example, in the parent study only 9% of family members who reported having a trusted relationship with a facility staff member identified a social worker as filling that role. Family and staff focus group participants in the dissertation study reported little social work involvement in meeting resident and family needs at the end of life, and resident focus group participants (who, with one exception, resided in facilities with social work staff) simply did not mention social workers at all. Family respondents scarcely mentioned social workers in the second paper (*A Good Death for Residents in Long-Term Care: Family Members Speak*) and were critical of social work services when they did.

Social Work Skills

Yet, social workers bring to these settings a unique set of skills and training including identification of community financial and psychosocial resources, skills to conduct a comprehensive assessment, a strengths based perspective, a theoretical perspective that relates clients to their environments, and the ability to recognize crises and provide crisis management (U.S. Department of Health and Human Services, 2006; Howe & Daratsos, 2006) that can contribute to effective end-of-life care. For example, one social work
intervention (i.e., a controlled clinical trial in a New York City nursing home involving 139 newly admitted residents) resulted in improved documentation of resident preferences and advance directives and greater congruence between resident wishes and treatments received (Morrison, Chichin, Carter, Burack, Lantz & Meier, 2005).

**Professional Initiatives**

There are national initiatives that underscore the importance of social work involvement in care at the end of life. In 2002 a Social Work Summit on End-of-Life and Palliative Care was sponsored by the Project on Death in America (PDIA), the Last Acts Campaign of the Robert Wood Johnson Foundation, and the Duke Institute on Care at the End of Life. The purpose of the summit was to develop a collaborative network of professionals (30 organizations were represented) and formulate a research agenda (Christ & Blacker, 2005). The PDIA also has sponsored the development of The Social Work End-of-Life Educational Project resulting in a currently-used, advanced training module (Csikai & Chaitin, 2006).

The National Association of Social Workers (2004) has developed Standards for Social Work in Palliative and End-of-Life Care which describe a minimal knowledge base including ten standards: ethics and values; knowledge; assessment; intervention and treatment planning; attitude/self awareness; empowerment and advocacy; documentation; interdisciplinary team work; cultural competence; and continuing education.

**Recommendation 1: Establish the Social Worker as a Preceptor in End-Of-Life Care**

The long-term care social worker is uniquely positioned to work with all the stakeholders involved in the end-of-life experience and is an ideal candidate to coordinate care, establish collaborative relationships among stakeholders, foster communication, and
negotiate crises. Therefore, social workers can be preceptors in palliative and end-of-life care within the facilities in which they work. In the absence of facility social workers, Hospice social workers can fill this role. In either case, professional social workers must step forward and become involved.

If facility social workers are not formally trained (i.e., do not have social work degrees from a CSWE school of social work or receive end-of-life training as part of their education), they should receive special training in the needs of families and residents at the end of life, bereavement, and family counseling. Further, BSW level social workers could also benefit from specialized training in geriatric social work as the BSW is a generalist degree.

Working with Staff: The social work preceptor can train all direct care staff (including dietary and housekeeping) and familiarize the staff with the psychosocial needs of families and residents at the end of life as well as involve medical personnel to describe the dying process. Prior studies have shown that staff welcome such training (Secrest, Iorio & Martz, 2005; Coffey, 2004; Zimmerman, Sloane, Hanson, Mitchell & Shy, 2003); however, it is not being provided (Coffey, 2004).

Staff focus group participants (both paraprofessional and licensed) reported high levels of attachment to residents and grief reactions to their deaths, findings substantiated in other studies (Rickerson, Somers, Allen, Strumpf & Cassarett, 2005). Social workers can arrange bereavement counseling for staff members by enlisting professional support (e.g., Hospice bereavement counselors) and/or developing in-service training regarding normal grief reactions and appropriate grief work.
**Working with Residents.** Social workers can provide considerable assistance in the transition to the long-term care environment from acute care settings, other residential settings, or private homes. This transition is often disruptive to medical services (Hanson & Ersek, 2006) and typically viewed as a crisis (Oleson & Shadick, 1993). It is important, then, that social workers meet with residents (and families) upon facility admission.

An interdisciplinary admissions conference is one model developed in practice settings which promotes easier transitions for residents and family. At this conference, the social worker begins to develop trusting relationships with residents and collaborative relationships with families that are important for a smooth transition into the facility and throughout the long-term care stay. Further, these relationships support discussions related to care at the end of life in which social workers can further elicit individual resident preferences. In addition, social workers provide information, forms (e.g., living wills, healthcare powers of attorney), and resources for planning end of life. By initiating this discussion upon admission, end-of-life planning can be integrated throughout the resident’s stay (Froggett & Payne, 2006).

However, in addition to individual end-of-life planning, resident focus group participants expressed concerns related to facility practices surrounding death and dying. They wished to be informed when other residents died and had strong feelings and opinions regarding how those deaths were handled. The social work preceptor can meet with residents to solicit input regarding facility end-of-life protocols.

**Working with Families.** Social workers can provide the same types of services to families as to facility staff and residents as family members often make healthcare decisions for residents and oversee care. However, family members present special challenges. While
family involvement is associated with residents’ well-being (Greene & Monahan, 1982), family members’ preferences regarding care at the end of life are at times incongruent with those of residents (Csikai & Bass, 2000).

Further, life-long relationships between family members and residents or among family members can be conflicted and ambiguous. Social workers can assist family members by encouraging them to visit and mediating strained relationships; however, it is sometimes challenging to address family needs while maintaining the ethical role of resident advocate (Csikai, 2004).

Physicians

The role of physicians in long-term care, especially nursing homes, is currently under scrutiny (Miller, Teno & Mor, 2004; Katz & Karuza, 2005). As consumer satisfaction with care has become an accepted measure of the quality of care, family and resident satisfaction with physician access and communication have emerged as areas in need of improvement (Shield, Wetle, Teno, Miller & Welch, 2005). This concern is particularly crucial at the end of life as care decisions require a physician’s prognostication and guidance and ideally follow a shared-decision making model (Bern-Klug, Gessert, Crenner, Buenaver & Skirchak, 2004).

Dissertation Findings

The findings of the dissertation studies confirm these issues. Family members and residents stated dissatisfaction with assigned facility physicians, describing them as unavailable and physician/family communication as poor or non-existent. Licensed staff and family focus group members laughed when asked about physician involvement and in one instance responded: “What physicians? There are none.”
Further, less than 85% of family and staff respondents were able to answer QOD-LTC items related to physicians’ discussions of death and dying and for incompetent decedents were unable to respond to items about the physicians’ personal knowledge of decedents and trust between the decedents and physicians. These findings support a picture of physicians who are inaccessible.

However, at the end of life, it is critical that physicians be available to family members and residents to provide professional insight into the dying process and explain medical treatment alternatives (Miller, Teno & Mor, 2004). Further, physician orders are required for implementing advance directives, comfort care measures, or Hospice referrals. Therefore, interventions are needed to improve physician communication with family and residents especially around issues related to medical decision making at the end of life.

Recommendation 2: Social Workers Act as Liaisons between Physicians, Residents and Families

Social workers can facilitate planned and effective conferences between physicians, residents, and family members regarding advance care planning, treatment alternatives, and prognoses. Social worker presence can support physician discussions of death and dying.

Paraprofessional Care Providers

There is little, yet necessary, discussion of paraprofessional care providers (also known as nursing assistants, nurses’ aides, healthcare assistants) within the literatures of nursing, end-of-life, or long-term care (Hall, et al., 2005). Yet, paraprofessional care providers are instrumental in determining the quality of care in long-term care settings and at the end of life (Black, 2004; Institute of Medicine, 1996). The few available studies provide important insight into motivations of these direct care workers who comprise 71% of the
long-term care workforce and provide 90% of the care (Institute on Medicine, 1996; Friedman, Daub, Cresci & Keyser, 1999).

Unfortunately, these studies (which are generally small and qualitative) describe paraprofessional care providers as performing physically demanding tasks, having the lowest status among staff in long-term care, being paid less than living wages, having little control over their work schedules, assignments or workload, and being excluded from discussions about resident care (Bowers, Esmond & Jacobson, 2003; Secrest, Iorio & Martz, 2005; Hare, Pratt & Andrews, 1988). These working conditions have lead to discouragement, feelings of futility, and perceptions of professional dismissal (Crickmer, 2005) in environments described as filled with conflict (Forbes, 2001).

Despite high annual turnover rates (Crickmer, 2005; Bowers, Esmond & Jacobson, 2003), approximately half of the paraprofessional workforce is stable (i.e., 50% of the workforce remain in place as 50% of the positions are turned over multiple times) (Institute on Medicine, 1996). These enduring care providers see themselves as called to their work (Black, 2004), remain invested in their jobs (Komaromy, Sidell & Katz, 2000), and see care provision as a meaningful and life-long career (Black). One research team describes them as possessing “a profound sense of purpose…an extraordinary degree of caring, empathy, intuition, and wisdom” (Secrest, Iorio & Martz, 2005, p. 95).

Further, relationships with residents (which are often described as familial) are a primary source of job satisfaction and the sense of belonging these relationships engender is the most important reason that care providers stay (Ersek & Wilson, 2003; Bitzan & Kruzich, 1990). Therefore, supporting the formation of relationships and recognizing
paraprofessionals’ contributions to care are essential for increased staff satisfaction and reduced turnover and consequent high quality of care (Miller, Teno & Mor, 2004).

**Recommendation 3: Implement Consistent Staffing Patterns**

One way to promote development of relationships that contribute to high quality end-of-life care is the use of consistent staffing patterns. These patterns, unlike more traditional rotational patterns, assign paraprofessional staff to the same residents each day. As these caregivers provide the most intimate of care (e.g., bathing, toileting and dressing), relationships develop from this close contact over time. Also, care providers who are familiar with individual residents recognize changes in resident status (Boockvar, Brodie & Lachs, 2000) and decline prior to impending death (Black, 2005). However, consideration must also be given to resident acuity and adjustments in staff assignments made to prevent staff stress or burnout in special care settings (Zimmerman, et al., 2005).

**Recommendation 4: Acknowledge Contributions of Paraprofessional Staff**

Current literature clearly demonstrates that nursing assistants receive little recognition for their work (Crickmer, 2005; Yeats, Cready, Ray, DeWitt & Queen, 2004; Bowers, Esmond & Jacobson, 2003). Conversely, research shows that supportive environments result in higher job satisfaction (Hall, et al., 2005), lower levels of burnout (Hare, Pratt & Andrews, 1988) and reduced staff turnover (Secrest, Iorio & Martz, 2005; Hegemnan, 2005; Havens & Aikens, 1999). Therefore, recognizing the contributions of these care providers is an important element in establishing a stable, competent long-term care workforce.

Within the paraprofessional focus groups, two methods of recognizing the contributions of these care providers consistently emerged: (a) inclusion in plans of care or family conferences in which their knowledge of residents is recognized; and (b) provision of
training. These interventions promote the professional status of these care providers and utilize valuable information that can contribute to higher quality end-of-life care. That staff desire to provide quality end-of-life care and welcome training are substantiated in other studies (Secrest, Iorio & Martz, 2005; Coffey, 2004; Zimmerman, Sloane, Hanson, Mitchell & Shy, 2003). These recommendations are grounded in common sense (Nakhnikian, 2005) and represent cost efficient ways to address a critical issue.
APPENDIX I:

Measures of the Quality of the Dying

QOD-LTC-C (Quality of Dying in Long-term Care, Cognitively Intact Decedents)

<table>
<thead>
<tr>
<th>I would like for you to think back over the last month of [RESIDENT'S] life. Here are some statements that have been considered important during the dying process. Please tell me how true each statement is for [RESIDENT].</th>
<th>Not at all</th>
<th>A little bit</th>
<th>A moderate amount</th>
<th>Quite a bit</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Although [HE/SHE] could not control certain aspects of [HIS/HER] illness, [RESIDENT] had a sense of control about [HIS/HER] treatment decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. [RESIDENT] participated as much as [HE/SHE] wanted in the decisions about [HIS/HER] care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. In general, [RESIDENT] knew what to expect about the course of [HIS/HER] illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. As [HIS/HER] illness progressed, [HE/SHE] knew where to go for answers to [HIS/HER] questions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. [RESIDENT] had a physician whom [HE/SHE] trusted.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. [HE/SHE] spent as much time as [HE/SHE] wanted with [HIS/HER] family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. There was someone in [HIS/HER] life with whom [HE/SHE] could share [HIS/HER] deepest thoughts.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. [RESIDENT] received compassionate physical touch daily.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
I would like for you to think back over the last month of [RESIDENT’S] life. Here are some statements that have been considered important during the dying process. Please tell me how true each statement is for [RESIDENT].

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>A moderate amount</th>
<th>Quite a bit</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.</td>
<td>[RESIDENT] had regrets about the way [HE/SHE] lived [HIS/HER] life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.</td>
<td>Thoughts of dying frightened [HIM/HER].</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11.</td>
<td>[HE/SHE] was able to say important things to those close to [HIM/HER].</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12.</td>
<td>[HE/SHE] was able to make a positive difference in the lives of others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13.</td>
<td>[HE/SHE] was able to help others through time together, gifts or wisdom.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14.</td>
<td>[HE/SHE] was able to share important things with [HIS/HER] family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15.</td>
<td>Despite [HIS/HER] illness, [HE/SHE] had a sense of meaning in [HIS/HER] life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16.</td>
<td>[HE/SHE] appeared at peace.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17.</td>
<td>[RESIDENT] had treatment preferences in writing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18.</td>
<td>[RESIDENT] felt prepared to die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19.</td>
<td>[RESIDENT] had funeral arrangements planned.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20.</td>
<td>[RESIDENT] had named a decision maker in the event [HE/SHE] was no longer able to make decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
I would like for you to think back over the last month of [RESIDENT’S] life. Here are some statements that have been considered important during the dying process. Please tell me how true each statement is for [RESIDENT].

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>A moderate amount</th>
<th>Quite a bit</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. [RESIDENT] was able to maintain [HIS/HER] sense of humor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. [RESIDENT] was able to maintain [HIS/HER] dignity.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. [RESIDENT] was at peace with God.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
I would like for you to think back over the last month of [RESIDENT’S] life. Here are some statements that have been considered important during the dying process. Please tell me how true each statement is for [RESIDENT].

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>A moderate amount</th>
<th>Quite a bit</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. There was a nurse or aide with whom [RESIDENT] felt comfortable.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. [RESIDENT] received compassionate physical touch daily.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. [HE/SHE] appeared to be at peace.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. [RESIDENT’S] physician knew [HIM/HER] as a whole person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. [RESIDENT] had treatment preferences in writing (either his/her own or by a surrogate decision maker).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. [RESIDENT] indicated [HE/SHE] was prepared to die.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. [RESIDENT’S] funeral arrangements were planned.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. [RESIDENT] had named a decision maker in the event [HE/SHE] was no longer able to make decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
9. [RESIDENT] was able to maintain [HIS/HER] sense of humor. | 1 | 2 | 3 | 4 | 5
10. [RESIDENT’S] dignity was maintained. | 1 | 2 | 3 | 4 | 5
11. [RESIDENT] was kept clean. | 1 | 2 | 3 | 4 | 5
REFERENCES


Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at end of life by patients, family physicians, and other care providers. *JAMA, 284*(19), 2476-2482.


